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adolescent health

VOLUME III: CROSSCUTTING ISSUES IN THE DELIVERY OF HEALTH AND RELATED SERVICES

J952-67

CONGRESS OF THE UNITED STATES
OFFICE OF TECHNOLOGY ASSESSMENT

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Foreword

Adolescence, the poet suggested, "is the one age [that] defeats the metaphor." In many respects, such as legal and financial dependence, adolescents are still children; in other respects, such as physical development, they approach and then reach adult status. In part because they experience profound biological, emotional, intellectual and social changes, adolescents as a group—and some adolescents more than others—are uniquely vulnerable to the impact of many of the Nation's social policies. For numerous reasons, policymakers and the public have long struggled with the establishment of appropriate health-related policies and programs for adolescents.

OTA's report responds to the request of numerous Members of Congress to review the physical, emotional, and behavioral health status of contemporary American adolescents, including adolescents in groups who might be more likely to be in special need of health-related interventions: adolescents living in poverty, adolescents from racial and ethnic minority groups, Native American adolescents, and adolescents in rural areas. In addition, OTA was asked to: 1) identify risk and protective factors for adolescent health problems and integrate national data in order to understand the clustering of specific adolescent problems, 2) evaluate options in the organization of health services and technologies available to adolescents (including accessibility and financing), 3) assess options in the conduct of national health surveys to improve collection of adolescent health statistics, and 4) identify gaps in research on the health and behavior of adolescents.

Senator Daniel K. Inouye, Chairman of the Senate Select Committee on Indian Affairs, and Senator Nancy Landon Kassebaum, Ranking Minority Member of the Subcommittee on Education, Arts, and Humanities of the Senate Committee on Labor and Human Resources, were the lead requesters of OTA's adolescent health study. Requesters included Chairmen or Ranking Minority Members of the Senate Appropriations Committee, the Senate Commerce, Science, and Transportation Committee, the Senate Finance Committee, the Senate Labor and Human Resources Committee, the Senate Small Business Committee, the Senate Veterans' Affairs Committee, and the House Interior and Insular Affairs Committee; and the Chairman and six senatorial members of the congressional Technology Assessment Board. A letter of support was received from the House Select Committee on Children, Youth, and Families.

This OTA assessment is being published in three volumes: Volume I, *Summary and Policy Options*; Volume II, *Background and the Effectiveness of Selected Prevention and Treatment Services*; and Volume III, *Crosscutting Issues in the Delivery of Health and Related Services*. Volume I was published in April 1991. Volume II will be available later in 1991. Two related reports have already been issued as part of this study (see appendix A in Volume I).

OTA was greatly assisted by an advisory panel, chaired by Felton Earls, Professor of Behavioral Sciences at the Harvard University School of Public Health. Michael I. Cohen, Chairman of the Department of Pediatrics at the Albert Einstein College of Medicine in New York, served as vice chairman. In addition, many individuals from academia, the Federal Government, the private sector, and the public provided information and reviewed drafts of the assessment. OTA would like to especially thank Carnegie Corporation of New York, and its operating program, the Carnegie Council on Adolescent Development, for their generous and diverse assistance throughout the course of this assessment. Finally, the members of our Youth Advisory Panel—a group of 21 individuals ages 10 through 19, who met often with OTA staff, with OTA's advisory panel, and with workshop participants—were essential to the study. These young people provided the adolescent perspective on health concerns of importance to young people, and made valuable suggestions for improving health services and health policy. The final responsibility for the content of the assessment rests with OTA.

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NOTE: OTA appreciates and is grateful for the valuable assistance and thoughtful critiques provided by the advisory panel members. The panel does not, however, necessarily approve, disapprove, or endorse this report. OTA assumes full responsibility for the report and the accuracy of its contents.

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*Supported by Carnegie Corporation of New York and the Carnegie Council on Adolescent Development.

Volume III

CROSSCUTTING ISSUES IN THE DELIVERY OF HEALTH AND RELATED SERVICES

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INTRODUCTION

This is Volume III of OTA's assessment, *Adolescent Health*. This volume addresses a number of crosscutting issues in the delivery of health and related services to adolescents ages 10 to 18. As shown in box A, which lists the table of contents for all three volumes of the assessment, the following issues are discussed in this volume:[1]

- Chapter 15: Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents;
- Chapter 16: Financial Access to Health Services;
- Chapter 17: Consent and Confidentiality in Adolescent Health Care Decisionmaking;
- Chapter 18: Issues in the Delivery of Services to Selected Groups of Adolescents; and
- Chapter 19: The Role of Federal Agencies in Adolescent Health.

Chapter 15 reviews research on the shortcomings of the mainstream primary health care system with respect to adolescents, including the scarcity of specially trained providers. It also discusses recent innovations to improve the delivery of health and related services to adolescents. Prominent among these innovations are community-based and school-linked health centers, which at their best can simultaneously address a number of barriers to adolescents' receipt of basic health services. Other innovations, such as adolescent participation in the design of services, can also help to meet the demonstrated need for more user-friendly health services for adolescents. Even should the rate of these innovations be accelerated, the chapter makes clear that increased and improved training of health care providers is essential in order for adolescent health services to be more accessible and effective.

Chapter 16 addresses issues in financial access to health services. Financial access is key to any discussion of adolescents' access to health services, yet one out of seven adolescents are without any health insurance, and the percentage of adolescents who are uninsured is growing. Even when adolescents have health insurance, available benefit packages may not meet adolescents' special needs (e.g., their needs for preventive and early intervention services; for dental, mental health, substance abuse treatment, or for prenatal care; for services provided by nonphysician health care professionals, or in school settings). Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program theoretically provides the most generous and comprehensive benefits package, but one out of three poor adolescents does not have access to Medicaid, and average EPSDT spending on adolescents appears to be quite low. The promise of Medicaid in meeting the health care needs of the country's most disadvantaged adolescents appears not to have been fulfilled.

Chapter 17 turns to a third major issue affecting adolescents' access to health services: requirements for parental consent or notification. The chapter summarizes the body of law that determines how the authority for adolescent health care decisionmaking is allocated—including the extent of parental involvement in adolescent health care decisionmaking. The chapter summarizes the common law rule, the exceptions to the common law rule, the positions of health care provider organizations on issues in adolescent health care decisionmaking, and the research literature on the capacity of adolescents to make health care decisions on their own. Chapter 19 also provides a framework for conducting an analysis of the various interests that must be considered—those of the state, of parents, of health care providers, and of adolescents—should change in the existing situation be desired.

Chapter 18 addresses the health issues and barriers to effective and appropriate health services that are faced by selected groups of adolescents: those living in poverty, members of racial or ethnic minorities (black adolescents, Hispanic adolescents, Asian adolescents, American Indian and Alaska Native adolescents, Native Hawaiian adolescents), and residents of rural areas. In addition, the chapter reviews available knowledge on interventions designed to increase access to health services among these groups of adolescents. Federal programs and policies for poor adolescents, racial and ethnic minority adolescents, and adolescents living in rural areas are also assessed. The chapter takes on

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[1] The entire assessment is being published in three volumes: in addition to this volume, the reader can obtain *Volume I—Summary and Policy Options* (published in April 1991) and *Volume II—Background and the Effectiveness of Selected Prevention and Treatment Services* (to be published later in 1991).

Box A—Full Table of Contents for OTA's Adolescent Health Report

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Appendixes

A. Method of the Study
B. Acknowledgments
C. Issues Related to the Lack of Information About Adolescent Health and Health and Related Services
D. Glossary of Abbreviations and Terms

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1. Introduction

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2. What Is Adolescent Health?
3. Parents' and Families' Influence on Adolescent Health
4. Schools and Discretionary Time

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7. Nutrition and Fitness Problems: Prevention and Services
8. Dental and Oral Health Problems: Prevention and Services

Prevention and Services Related to Sexually Transmitted Diseases and Pregnancy

9. AIDS and Other Sexually Transmitted Diseases: Prevention and Services
10. Pregnancy and Parenting: Prevention and Services

Prevention and Services Related to Mental Health Problems

11. Mental Health Problems: Prevention and Services
12. Alcohol, Tobacco, and Drug Abuse: Prevention and Services

Prevention and Services Related to Delinquency and Homelessness

13. Delinquency: Prevention and Services
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Appendix

A. Glossary of Abbreviations and Terms

VOLUME III: CROSSCUTTING ISSUES IN THE DELIVERY OF HEALTH AND RELATED SERVICES

15. Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents
16. Financial Access to Health Services
17. Consent and Confidentiality in Adolescent Health Care Decisionmaking
18. Issues in the Delivery of Services to Selected Groups of Adolescents
19. The Role of Federal Agencies in Adolescent Health

Appendixes

A. Glossary of Abbreviations and Terms
B. Burden of Health Problems Among U.S. Adolescents
C. HCFA's Method for Estimating National Medicaid Enrollment and Expenditures for Adolescents

importance as one considers that the population of the United States is becoming increasingly racially and ethnically diverse, and that racial and ethnic minority adolescents—as well as rural adolescents—are more likely than white adolescents to face the health risks associated with living in poverty. Sadly, the systematic knowledge base on assisting these adolescents is as yet underdeveloped.

Chapter 19 provides an overview of the Federal role in adolescent health. The chapter is based primarily on the results of an OTA survey of

Box B—Summary of Major Policy Options

OTA suggests a range of options that could be implemented in an effort to help improve adolescent health, broadly defined. Three major options that OTA believes Congress may want to consider are:

1. improving U.S. adolescents' access to appropriate health services,
2. restructuring and invigorating Federal efforts to improve adolescent health, and
3. improving adolescents' environments.

Strategies to improve U.S. adolescents' access to appropriate health services include:

- support the development of centers that provide, in schools and/or communities, comprehensive and accessible services designed specifically for adolescents—e.g., by providing seed money, continuation funding, or removing existing financial barriers;
- increase financial access—e.g., by expanding Medicaid to immediately include all poor adolescents, by increasing access to private insurance, and by increasing outreach for Medicaid;
- increase legal access to health services—e.g., by supporting the development of a model State statute, or requiring or conditioning States' receipt of Federal moneys for specific programs on substantive changes in consent and confidentiality regulations;
- increase support for training for the providers of health and related services; and
- empower adolescents to gain access to health and related services—for example, through education and encouraging adolescent participation in the design of services.

Strategies to restructure and invigorate Federal efforts to improve adolescent health include:

- create a new locus for a strong Federal role in addressing adolescent health issues;
- strengthen traditional U.S. executive branch activities in: 1) program development for promising or neglected areas of intervention, 2) research, and 3) data collection.

Strategies to improve the social environment for adolescents include:

- increase support to families of adolescents—e.g., through tangible supports such as child allowances or more flexible working hours, and through providing information on appropriate, health-promoting parenting for adolescents;
- support additional limitations on adolescents' access to firearms;
- support the expansion of appropriate recreational opportunities for adolescents; and
- monitor the effects on adolescents of the implementation of the National and Community Service Act of 1990.

In addition to these major options and strategies, which cut across the areas examined by OTA, a number of topic-specific policy options are listed in Volume I of the Report.

It is important to note that, apart from whatever specific strategies the Federal Government may adopt to improve adolescents' health, **there is a need for a basic change in approach to adolescent health issues in this country, so that adolescents are approached more sympathetically and supportively, and not merely as individuals potentially riddled with problems and behaving badly.**

numerous Federal agencies identified by OTA as having a role or potential role in adolescent health. The survey was followed by a meeting between U.S. executive branch representatives and OTA staff and advisors. The chapter concludes that funding for adolescent health issues—including research and services—is meager, that existing interagency coordination efforts are ineffective, and that Federal leadership specific to adolescent health issues is urgently needed.

Although each chapter in this volume (and in Volume II) ends with a section on conclusions and policy implications, specific legislative options relevant to each of the issues discussed in Volume III can be found in *Volume I—Summary and Policy Options* of this assessment.[2] In addition, many of the major policy options that were suggested by OTA's full analysis of adolescent health issues focus on issues discussed in this volume. OTA's major policy options are briefly summarized in box B.

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[2] See the back of this Report for an order form.

In order to provide context on the extent of a number of adolescent health concerns, **appendix B** in this Volume summarizes data from Volume II on the prevalence and incidence of the broad range of health concerns found among adolescents. **Appendix A** is a glossary of terms and abbreviations, and **appendix C** provides technical details on the Health Care Financing Administration's method for estimating national Medicaid enrollment and expenditures for adolescents. The many individuals who assisted OTA in the development of the three volumes of this Report are listed in Appendix B of Volume I. The way OTA went about conducting the assessment—including lists of workshop participants and members of the Youth Advisory Panel—is described in Appendix A of Volume I. The requesters of the assessment are listed in box C below.

Box C—Requesters of OTA's Adolescent Health Report (with current committee chair or ranking minority assignments)

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Senator Nancy Landon Kassebaum, Ranking Minority Member of the Subcommittee on Education, Arts, and Humanities of the Senate Committee on Labor and Human Resources;
Senator Bob Dole, Minority Leader of the Senate;
Senator Robert C. Byrd, Chairman of the Senate Committee on Appropriations;
Representative William H. Gray, III, Majority Whip of the House of Representatives;
Senator James M. Jeffords, Ranking Minority Member of the Subcommittee on Labor of the Senate Committee on Labor and Human Resources;
Senator Orrin G. Hatch, Ranking Minority Member of the Senate Committee on Labor and Human Resources;
Senator Edward M. Kennedy, Chairman of the Senate Committee on Labor and Human Resources;
Senator Quentin W. Burdick, Chairman of the Senate Committee on Environment and Public Works;
Senator Mark O. Hatfield, Ranking Minority Member of the Senate Committee on Appropriations;
Senator Alan K. Simpson, Assistant Minority Leader of the Senate;
Senator Alan Cranston, Chairman of the Senate Committee on Veterans Affairs;
Senator Ted Stevens, Ranking Minority Member of the Senate Committee on Rules and Administration;
Senator Bob Packwood, Ranking Minority Member of the Senate Committee on Finance;
Senator Charles Grassley, Member of the Technology Assessment Board;
Senator Barbara Mikulski, Chairman of the Subcommittee on Veterans Affairs, Housing and Urban Development, and Independent Agencies of the Senate Committee on Appropriations;
Senator Ernest Hollings, Chairman of the Senate Committee on Commerce, Science, and Transportation;
Senator Arlen Specter, Ranking Minority Member of the Subcommittee on Veterans Affairs;
Representative Henry A. Waxman, Chairman of the Subcommittee on Health and the Environment of the House Committee on Energy and Commerce;
Senator Daniel K. Akaka;
Representative Morris K. Udall, Chairman of the House Committee on Interior and Insular Affairs;
Senator Frank H. Murkowski, Vice Chairman of the Senate Select Committee on Intelligence;
Senator Christopher J. Dodd, Chairman of the Subcommittee on Children, Family, Drugs, and Alcohol of the Senate Committee on Labor and Human Resources;
Senator Claiborne Pell, Chairman of the Senate Committee on Foreign Relations;
Senator Dale Bumpers, Chairman of the Senate Committee on Small Business;
Senator Lloyd Bentsen, Chairman of the Senate Committee on Finance;
Senator Daniel P. Moynihan, Chairman of the Subcommittee on Social Security and Family Policy of the Senate Committee on Finance;
Senator John D. Rockefeller, IV, Chairman of the Subcommittee on Medicare and Long Term Care of the Senate Committee on Finance;
Representative Don Young, Ranking Minority Member of the House Committee on Interior and Insular Affairs.

A letter of support was received from the House Select Committee on Children, Youth, and Families.

Chapter 15

MAJOR ISSUES PERTAINING TO THE DELIVERY OF PRIMARY AND COMPREHENSIVE HEALTH SERVICES TO ADOLESCENTS

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Chapter 15

MAJOR ISSUES PERTAINING TO THE DELIVERY OF PRIMARY AND COMPREHENSIVE HEALTH SERVICES TO ADOLESCENTS

Introduction

This chapter addresses several important issues in the delivery of primary health care services for adolescents in the United States.[1] It begins by presenting available data on adolescents' visits to private office-based physicians and then reviews a number of questions related to physicians' interest in and ability to care for adolescents. How welcome are adolescents in physicians' practices? How much time do office-based physicians spend with adolescent patients? Because adolescents may not have some of the kinds of physical health problems that typically bring younger or older individuals to the doctor, some physicians have suggested that professional time spent with adolescents be used to assess the presence of a variety of social and behavioral risk factors and morbidities (e.g., quality of family life, school performance, substance use, engagement in sex), and to provide assistance to adolescents on these issues (10). The need for appropriate attention to such issues by health care professionals and others who see adolescents is well documented in Volume II of this Report, ''Background and the Effectiveness of Selected Prevention and Treatment Services.'' (Also see app. B to this volume, ''Burden of Health Problems Among U.S. Adolescents.'') But are primary care physicians and other health care professionals who come into contact with adolescents able to recognize and treat adolescent health problems? How competent are health care professionals in caring for adolescents?

Photo credit: Benjamin Smith, Washington, DC

Adolescents are commonly regarded as the healthiest of Americans, yet OTA's analysis suggests that adolescents do have health problems and problems gaining access to services.

The analysis in this chapter suggests that improvements in the training and education of physicians who see adolescents and the training of additional specialists in adolescent health care are needed. The analysis also cites evidence that the mainstream model of health service delivery—which relies chiefly on the provision of care by private office-based physicians who wait for patients to seek them out[2]—does not fully meet the needs of U.S. adolescents. In recent years, several innovations in health service delivery have attempted to meet the needs of adolescents. The most prominent of these efforts—adolescent health care clinics, so-called ''free'' clinics, multiservice centers, school-linked health centers (SLHCs), and efforts to involve adolescents in health services planning and management—are described in this chapter. The chapter concludes with a discussion of possibilities for Federal action to improve the delivery of health services to U.S. adolescents.

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[1] A unified definition of primary care that clearly distinguishes it from specialty care does not exist (262,263). An early definition of primary care that was published in 1973 included the following elements: first contact care, comprehensive care, coordinated or integrated care, and care that is longitudinal over time rather than episodic (263). First contact care is the extent to which a patient contacts the source of care whenever he or she perceives a new need for care. Coordination of care entails a medical provider's ability to provide for continuity of information from visits to other providers (e.g., specialists and emergency facilities) as well as from earlier visits to him or herself. Longitudinality of care is the extent to which a provider serves as a source of care over time regardless of the presence or absence of a particular type of problem (263).

[2] The ''waiting'' stance in health care delivery, in which health care providers physically remain in a service system and wait for patients to seek them out, has been distinguished from the ''seeking'' model, in which health care providers make themselves more accessible to potential patients (219,308).

Utilization of Ambulatory Care by U.S. Adolescents

Visits by Adolescents to Physicians

Data pertaining to the utilization of outpatient services by U.S. adolescents are quite limited. The 1985 National Ambulatory Medical Care Survey (NAMCS) conducted by the National Center for Health Statistics (NCHS) in the U.S. Department of Health and Human Services (DHHS) provides some data on *visits to non-Federal office-based physicians*, but the reader should keep in mind that NAMCS has numerous limitations.[3] The chief limitation of NAMCS is that it is a survey of physicians rather than of patients. Because many racial and ethnic minorities and Medicaid recipients do not get their health care from private office-based physicians, their health care utilization is not accurately reflected in NAMCS data. Another limitation of NAMCS is that it excludes ambulatory visits to physicians in hospital-based outpatient departments; family planning clinics; government-operated clinics for sexually transmitted diseases, and maternal and child health; SLHCs; hospital emergency facilities; and other sources of care used by adolescents. Further, at least some adolescents may not be willing to seek a private physician's care for certain problems. One survey of suburban high school students found that the majority would not go to a private physician for their concerns about sexuality, substance abuse, or emotional upset and also would not be willing to seek care for these problems with their parents' knowledge (175).[4]

Information about *physician contacts* is collected in another NCHS survey, the National Health Interview Survey (NHIS) (287).[5] NHIS is a continuing nationwide survey of households, in which data about health status and some aspects of health services utilization, including physician contacts, are collected from a probability sample of the civilian noninstitutionalized population residing in the United States. The 1988 NHIS included a special focus on the health status of children and adolescents through age 17 (287), but information on children and adolescents under age 17 was collected from a proxy respondent (typically the mother). NHIS requests and reports information not just about office visits to physicians but about all physician *contacts*, whether in person or by telephone, for examination, diagnosis, treatment, or advice, although office and clinic visits are reported separately to some extent (287). With two exceptions—the exclusion of physician contacts with hospital inpatients and the exclusion of physician contacts for mass screenings (e.g., in a trailer)—physician contacts mentioned by NHIS respondents are not restricted by type of setting or funding source. As in NAMCS, a contact is considered to be a physician contact if the service is provided directly by the

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[3] See ch. 6, ''Chronic Physical Illnesses: Prevention and Services,'' in Vol. II. In summary, NAMCS is a probability sample survey of office-based physicians, conducted annually from 1975 through 1981 and again in 1985 (286). The focus of the 1985 NAMCS is on office visits made within the coterminous United States (i.e., excluding Alaska and Hawaii) by ambulatory patients to nonfederally employed physicians who are principally engaged in office-based patient care practice, but not in the specialties of anesthesiology, pathology, or radiology. Telephone contacts and nonoffice visits are excluded from the NAMCS. The 1985 NAMCS physician *universe* included 276,430 doctors of medicine and 11,776 doctors of osteopathy; but the 1985 NAMCS *eligible physician sample* included 4,104 physicians, and only 2,879 physicians (70.2 percent of eligible sampled physicians, and 1 percent of physicians in the survey universe) actually participated in the survey. Responding physicians were asked to complete a survey instrument, following the NAMCS design, for a single week in the survey year. The 1985 NAMCS responding sample physicians completed a total of 71,594 patient records. Physicians are not requested to oversample for any particular patient populations (e.g., adolescents). NAMCS includes visits to private physicians' offices; non-hospital-based, free-standing clinics; groups, partnerships; staff-model health maintenance organizations, neighborhood health centers, and privately operated clinics (except family planning clinics) (286). For purposes of NAMCS, an ''office'' is defined as ''premises identified by physicians as locations for their ambulatory practices, customarily including consultation, examination, or treatment spaces the patients associate with a particular physician'' (286). The 1985 survey design, and comparisons of 1985 findings with those for 1975 to 1981, are described more fully in the NCHS publication, *The National Ambulatory Medical Care Survey: United States, 1975-81 and 1985 Trends* (286). However, as do many Federal publications, that publication typically disaggregates data for ages under 15 and 15 to 24 (see app. C, ''Issues Related to the Lack of Information About Adolescent Health and Health and Related Services'' in Vol. I of this Report).

[4] The mean age of these respondents was 15.4 years, 52 percent were female, and 95 percent were white. Most had ready access to medical care; 90 percent used a specific private physician. The sample included 649 students in grades 9 to 12.

[5] NHIS and data it collects on the health status of adolescents are described more fully in ch. 6, ''Chronic Physical Illnesses: Prevention and Services,'' in Vol. II.

Table 15-1—Visits to Private Office-Based Physicians by U.S. Adolescents Ages 10 to 14 and 15 to 18, by Sex, 1985

Sex and age	Number of visits in thousands	Percentage distribution	Number of visits per person per year[a]
Both sexes			
Ages 10 to 18	50,218	100.0%	1.6
10 to 14 years	23,852	47.5	1.4
15 to 18 years	26,366	52.5	1.8
Female			
Ages 10 to 18	27,041	53.8	1.7
10 to 14 years	11,974	23.8	1.4
15 to 18 years	15,067	30.0	2.1
Male			
Ages 10 to 18	23,177	46.2	1.4
10 to 14 years	11,878	23.7	1.4
15 to 18 years	11,299	22.5	1.5

[a] Rates are based on estimates of the civilian, noninstitutionalized adolescent population, excluding Alaska and Hawaii, as of July 1, 1985.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1985 National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

physician or by a nurse or other person acting under a physician's supervision.

NAMCS data show that the rate of visits to private office-based physicians by U.S. adolescents ages 10 through 18 in 1985 was 1.6 visits per person per year (see table 15-1)—far less than the nationwide average of 2.7 visits for all ages (285,286,288). Female adolescents made an average of 1.7 visits per person that year, while male adolescents made an average of 1.4 visits per person (288). Older female adolescents (ages 15 to 18) made more visits per person than either younger female adolescents (ages 10 to 14) or adolescent males of all ages. On average, female adolescents ages 15 to 18 saw a private office-based physician 2.1 times per year (288). There were no significant utilization differences between older and younger male adolescents (288).

Data from NHIS are not completely comparable to those from NAMCS; however, the 1988 NHIS also suggests that adolescents have among the lowest rates of physician contacts of any age groups in the United States.[6] Except for females ages 15 to 17, who would be expected to have a higher number of physician contacts due to pregnancies,[7] adolescents ages 12 to 14 and 15 to 17 had the lowest rates of visits among those under age 18.[8]

Figure 15-1 shows NAMCS data on the distribution of visits to private office-based physician specialists who cared for adolescents in 1985 by physician specialty. NAMCS found that more than one-third of adolescent visits in 1985 were to general and family practice physicians (288). Another one-quarter of adolescent visits were to pediatricians. Adolescents ages 15 to 18 were much more likely than 10- to 14-year-olds to see dermatologists and obstetrician/gynecologists (288). More than 9 percent of older adolescents' visits were to dermatologists, as compared with 3.5 percent of the younger adolescents' visits. Visits to obstetrician/gynecologists accounted for 7.4 percent of older adolescents' visits but only 1.1 percent of younger adolescents' visits. These differences probably reflect the greater proportion of older adolescents who seek treatment

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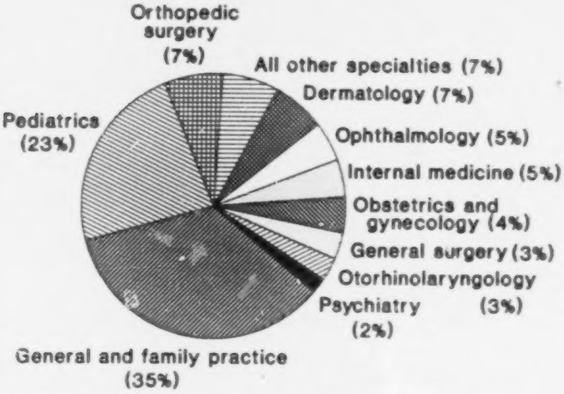
[6] NHIS found that persons ages 18 to 24 had the lowest rate of physician contacts.

[7] See ch. 6, "Chronic Physical Illness: Prevention and Services," in Vol. II, for a discussion of reasons for visits to office-based physicians.

[8] NCHS did not separate visits from telephone contacts, or visits by place separately for 12- to 17-year-old adolescents, but for 5- to 17-year-olds in the aggregate, the rate of *visits to physicians' offices not located in a hospital, health maintenance organization (HMO), or clinic* was 1.9 per person in 1988, lower than for all other age groups. Across all age groups, the number of office visits per person in 1988 was 3.2. Persons age 65 and over had the highest rate (5.1 for 65- to 74-year-olds, and 5.7 for those age 75 and over), followed by persons under 5 years (4.1), 45 to 64 (3.6), 25 to 44 (3.0), and 18 to 24 (2.1) (287). Similarly the rate of *visits to physicians in hospitals* (including emergency rooms, clinics, and doctor's offices located in a hospital (287)) (0.4 per person per year) and *other sites* (includes any place not classified into the other categories, including clinics and HMOs not located in hospitals (287) (0.4 per person per year) was lower for 5- to 17-year-olds than for all other age groups (287). The rate of telephone contacts was also lowest for 5- to 17-year-olds compared to the other age groups shown by NCHS (287).

Figure 15-1—Visits to Private Office-Based Physicians by U.S. Adolescents Ages 10 to 18, by Physician Specialty, 1985[a]

Estimated number of visits = 50,218,000



[a]Percentages may not add up to 100 because of rounding.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1985 National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

for acne and the higher rates of sexual activity and pregnancy among older female adolescents.[9]

Another finding of NAMCS was that over half of the U.S. adolescents visiting a private office-based physician in 1985 had a diagnostic test or procedure (288). Blood pressure checks, urinalysis, blood tests, and other lab tests were the most common (see table 15-2).

According to NAMCS, more than one-fourth (28 percent) of the adolescents who visited private office-based physicians in 1985 received some type of nonmedication therapy (288). Ambulatory surgery and counseling (other than diet counseling, family planning, or psychotherapy) were the most common (see table 15-3).

Some type of followup was planned for most (82 percent) of the adolescents who visited a private office-based physician in 1985; nearly half (47 percent) required a return visit (288) (see figure 15-2). There were very few referrals to other health care providers, however.

According to NAMCS, most adolescents (62 percent) spent between 6 and 15 minutes during the course of a private office-based physician visit in 1985 (288) (see figure 15-3). Only 4 percent spent more than half an hour. Half of all visits (49 percent) took 10 minutes or less. The average length of a visit was 14 minutes, slightly less than the average length of a visit for persons of all ages (16.5 minutes (286)).

As noted earlier, NAMCS data have limited use in examining utilization differences by race and ethnicity. Still, some interesting comparisons can be made. NAMCS found that black adolescents visited private office-based physicians in 1985 at about half the rate of white adolescents (0.9 v. 1.7 visits per person) (see table 15-4) (288). The majority (89.2 percent) of visits to private office-based physicians were made by white adolescents; black adolescents accounted for 8.7 percent of visits and Hispanics, 7.3 percent.[10] The 1988 NHIS report on adolescents, which distinguished only between black and white adolescents, supported the NAMCS finding that nonwhite adolescents have less physician contact than do white adolescents (287). Black adolescents ages 12 to 17 averaged 2.2 physician contacts in 1988, as compared with 3.6 physician contacts for white adolescents ages 12 to 17 (287).[11]

An important consideration in evaluating utilization of—and, by inference, access to—care among adolescents from racial and ethnic minorities is that differences in utilization may more accurately reflect socioeconomic status (and financial access) than racial and ethnic background.[12] It is not

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[9] See ch. 6, "Chronic Physical Illnesses: Prevention and Services," in Vol. II, for further discussion of chronic physical illnesses and ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II, for information on pregnancy and parenting among adolescents.

[10] Percents do not add to 100 because individuals could be identified on the NAMCS patient record as both black/white and Hispanic/non-Hispanic (286). (Other racial categories are "Asian/Pacific Islander" and "American Indian/Alaska Native" (286).) The racial/ethnic distribution of the NAMCS adolescent patient population is almost identical to the all ages population in NAMCS: according to NAMCS, 90 percent of NAMCS patients were white, and 10 percent were "black and other" in 1985 (and in the years 1975 through 1981) (286). Further breakdowns for all ages are not provided in NAMCS publications (e.g., 286); they are available as unpublished data from NCHS, but often the numbers of nonwhite patients are too small to be statistically reliable, especially if further disaggregated by age groups (288).

[11] As of July 1, 1988, approximately 81 percent of the adolescent population (ages 10 to 18) was white (both Hispanic and non-Hispanic); 16 percent was black (including Hispanic and non-Hispanic); and 10 percent was Hispanic (of any race).

[12] Issues in financial access to health services are discussed in ch. 16, "Financial Access to Health Services," in this volume. The relationship between poverty and racial and ethnic background, and nonfinancial issues in delivery of health and related services to poor adolescents and racial and ethnic minority adolescents, are discussed in ch. 18, "Issues in the Delivery of Services to Selected Groups of Adolescents," in this volume.

Table 15-2—Visits to Private Office-Based Physicians by U.S. Adolescents Ages 10 to 18, by Diagnostic Service and Sex, 1985

Diagnostic service	Number of visits in thousands	Both sexes[a]	Female adolescents[a]	Male adolescents[a]
None	22,751	45.3%	40.9%	50.4%
Blood pressure check	12,463	24.8	28.7	20.3
Urinalysis	7,130	14.2	17.0	10.9
Other lab test	5,887	11.7	14.1	8.9
Hematology	5,044	10.0	11.4	8.5
Glucose test	4,232	8.4	10.9	5.6
Other	4,083	8.1	7.8	8.4
Visual acuity	3,932	7.8	7.2	8.6
Radiology	4,379	8.8	7.2	10.5
Pelvic exam	2,813	5.6	10.4	—
Blood chemistry	2,014	4.0	3.4	4.7
Breast exam	1,809	3.6	6.5	0.2
Pap test	1,228	2.4	4.5	—
Rectal exam	1,118	2.2	3.5	0.7

[a] Percentages may not total to 100 because some visits may have included more than one service.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1985 National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

Table 15-3—Visits to Private Office-Based Physicians by U.S. Adolescents Ages 10 to 18, by Nonmedication Therapy Ordered or Provided, 1985

Nonmedication therapy	Number of visits in thousands	Percentage[a]
None	36,016	71.7%
Ambulatory surgery	4,406	8.8
Other counseling	4,293	8.5
Physiotherapy	1,935	3.8
Diet counseling	1,460	2.9
Family planning	1,070	2.1
Psychotherapy	998	2.0
Corrective lenses	842	1.7
Other	789	1.6

[a] Percentages may not total to 100 because some visits may have included more than one therapy.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1985 National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

possible to analyze NAMCS data by patient socioeconomic status, and the 1988 NHIS did not present physician contact information by family income level for adolescents. NHIS did, however, present physician contact information by family income level for all children and adolescents under age 18 combined. NHIS found that children and adolescents in families with incomes between $10,000 and $19,999 were the least likely of all children and adolescents to have had any physician contact (75.3 percent had at least one contact) and had the lowest number of contacts per person per year (3.5) (287). Children and adolescents in families with incomes below $10,000 had slightly fewer physician contacts (4.4) than those with incomes between $20,000 and $34,999 (4.6), and even fewer than those with incomes of $35,000 or more (5.2) (287a).

Adolescent Hospitalizations

Hospitalization is a fairly rare event for U.S adolescents. NHIS found that only 2.2 percent of 12- to 14-year-olds and 4.7 percent of 15- to 17-year-olds (3.5 percent when hospitalizations for infant delivery were excluded for 15- to 17-year-olds) were reported as having been hospitalized in 1988 (287).[13] These were the next to the lowest rates among all age groups shown in the NHIS report; only 5- to 11-year-olds had a lower hospitalization rate (287).[14] [15]

To some extent, the black-white differences found in physician contacts for ambulatory care are also found with respect to hospitalizations. According to the 1988 NHIS, 1.7 percent of black 12- to 14-year-

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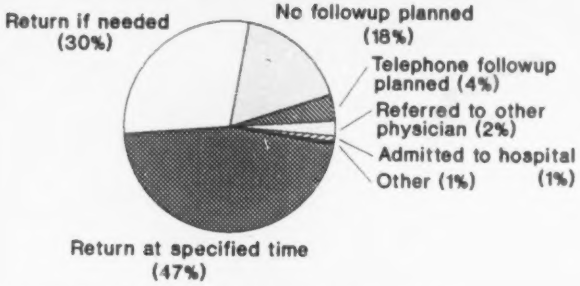
[13] In the NHIS definition, a hospitalization (''hospital episode'') is ''any continuous period of stay of 1 night or more in a hospital as an inpatient except the period of stay of a well newborn infant'' (287).

[14] The rates were 2.5 percent for 5- to 7-year-olds and 2.0 percent for 8- to 11-year-olds (287). Across all age groups, 5.4 percent of persons reported having been hospitalized in 1988; after age 18, the rate increased with age to 14.2 percent for those 75 and over (287).

[15] The leading reasons for hospitalization of 10- to 18-year-olds are discussed in ch. 6, ''Chronic Physical Illnesses: Prevention and Services,'' in Vol. II.

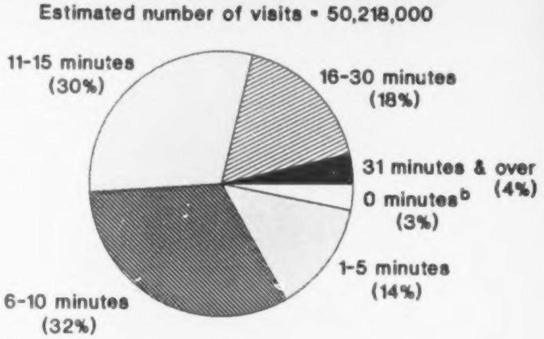
Figure 15-2—Visits to Private Office-Based Physicians by U.S. Adolescents Ages 10 to 18, by Disposition, 1985[a]



[a]Percentages may not add to 100 because of rounding.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1985 National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

Figure 15-3—Visits to Private Office-Based Physicians by U.S. Adolescents Ages 10 to 18, by Duration of Visit, 1985[a]



[a]Percentages may not add to 100 because of rounding.
[b]Represents office visits in which there was no face-to-face contact between the patient and the physician.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1985 National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

olds and 3.5 percent of black 15- to 17-year-olds[16] were reported hospitalized in 1988, as compared with 2.3 percent of white 12- to 14-year-olds, and 3.6 percent of white 15- to 17-year-olds[17] (287). However, the lower the family income, the more likely children and adolescents are to be hospitalized, according to NHIS data (287).[18]

Guidelines for Screening and Well-Child Care Visits

Little is known about what health screening periodicity is most appropriate and effective for adolescents, especially those at high risk for the common morbidities of adolescence. The American Academy of Pediatrics recommends that, from ages 10 to 18, adolescents should be screened every 2 years (10). The U.S. Preventive Services Task Force concluded that, from ages 7 to 18, except for routine pap smears for sexually active females ages 13 to 18 and a tetanus-diphtheria booster for all adolescents between ages 14 and 16, the scheduling of additional visits and the frequency of individual preventive services should be left to clinical discretion because of lack of data and differing patient risk profiles (291).

Many physicians subscribe to the recommendation by some (e.g., 174) that adolescents should visit a physician for well-child care and anticipatory guidance at least once a year (28). OTA has not examined the efficacy of any recommended schedules for routine periodic screening of adolescents.[19]

Health Care Professionals' Interest in and Ability To Care for Adolescents[20]

Attitudes of Pediatricians Toward Accepting Adolescents Into Their Practices

Since 1972, the American Academy of Pediatrics has officially endorsed pediatric care to continue until age 21 and even beyond 21 years for certain

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[16] These figures exclude deliveries; with deliveries, 5.8 percent of black 15- to 17-year-olds were reported hospitalized.

[17] These figures exclude deliveries; with deliveries, 4.5 percent of white 15- to 17-year-olds and 5.8 percent of black 15- to 17-year-olds were reported hospitalized. Racial differences in pregnancy and birth rates are discussed more fully in ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

[18] According to NHIS, 5.8 percent of children and adolescents under age 18 with family incomes less than $10,000 were hospitalized in 1988, compared to 4.0 percent with family incomes between $10,000 and $19,999, 3.4 percent with family incomes between $20,000 and $34,999, and 2.8 percent with family incomes of $35,000 or more (287).

[19] The cost-effectiveness of well-child-care visits for younger children was examined by OTA in its 1988 report *Healthy Children: Investing in the Future* (274a).

[20] Much of this section describes evidence that can be interpreted as somewhat critical of physicians', in particular pediatricians', interest in and ability to care for adolescents. A major reason the chapter discusses pediatricians in particular is that almost all information has been collected from and by pediatricians. Thus, this group has also taken the lead in examining its own abilities to care for adolescents.

Table 15-4—Visits to Private Office-Based Physicians by U.S. Adolescents Ages 10 to 18, by Patient's Race and Ethnicity, 1985

Patient's race and ethnicity	Number of visits in thousands	Percentage distribution	Number of visits per person per year[a]
All visits	50,218	100.0%	1.6
Race			
White	44,812	89.2	1.7
Black	4,365	8.7	0.9
Other	1,040	2.1	1.1
Ethnicity			
Hispanic	3,653	7.3	NA
Not Hispanic	46,564	92.7	NA

NA = Not available.

[a] Rates are based on estimates of the civilian noninstitutionalized population of the United States, excluding Alaska and Hawaii, as of July 1, 1990.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1985 National Ambulatory Medical Care Survey, Hyattsville, MD, 1989.

young people with chronic illness or disability (15). A study of Midwestern physicians conducted in 1980 to 1981 found, however, that only 40 percent of pediatricians continued adolescent care to the age of 18 (226). Pediatricians' practice policies for cutoff ages differed for accepting new patients into their practices and continuing a professional relationship with established adolescent patients. Sixteen percent of pediatricians would not accept a new patient into their practices who had reached the age of 15, and 42 percent would not accept a new patient who had reached the age of 16. For adolescent patients already established in a pediatric practice, 7 percent of pediatricians would end their care by the time the patient reached 15 years, and 20 percent by the time the patient became 16 years old.

In general, the pediatricians participating in this study who had low self-assessed competence in handling traditional adolescent problems (especially in contraceptive needs and emotional problems) were more likely to use age cutoff policies than others (226). However, insufficient training in adolescent medicine and discomfort with adolescents were not usually given as reasons for pediatricians' use of an adolescent age cutoff policy (12 and 7 percent of responses, respectively). The most frequent reason cited for an age cutoff policy was a group practice's preestablished decision (37 percent of responses) rather than a decision made by an individual pediatrician participating in the survey. This study also reported that almost 90 percent of pediatricians did not anticipate any further changes in their practices' age cutoff policies (226). More recent information concerning physician age cutoff policies is not available.

Midwestern physicians practicing general-family medicine, obstetrics/gynecology, pediatrics, internal medicine, and psychiatry have also been surveyed by mail (207). In general, these physicians were only moderately interested in adolescent health care, with only 28 percent of the sample expressing a definite interest. The return rate of this survey was only 34 percent; however, one can surmise that nonparticipating physicians were even less interested in adolescent health care than were respondents.

Time Spent With Adolescent Patients

How Much Time Do Office-Based Physicians Spend With Adolescent Patients?

As noted earlier, the 1985 NAMCS found that the most common amount of time that private office-based physicians spent with adolescent patients was between 6 and 10 minutes; the second most common amount of time was between 11 and 15 minutes (see figure 15-3).[21] An earlier national study of pediatricians determined that, on average, the duration of visits was 11.0 minutes with younger adolescents (ages 10 to 14) and 11.6 minutes with older adolescents (ages 15 to 19). Pediatricians spent an average of approximately 1 minute more with adolescents than they did with other noninfant patients (115).

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[21] It is interesting to note that length of visits to school-linked health centers (SLHCs) by adolescents is substantially longer. The Robert Wood Johnson Foundation has found that more than 80 percent of the visits to the 23 SLHCs that it supported in the 1988-89 and 1989-90 school years lasted more than 10 minutes and 46 percent lasted more than 20 minutes (see section below entitled "Innovations in the Delivery of Health and Related Services to Adolescents").

How Much Anticipatory Guidance Do Adolescent Patients Receive?

An area of specific physician behavior that many believe could enhance adolescents' health is "anticipatory guidance," or counseling about topics important for health and well-being. The American Academy of Pediatrics recommends that pediatricians routinely address a range of topics with adolescent patients (10).[22] Clearly, helpful discussion can be time-consuming. It should be noted, however, that very few pediatricians (fewer than 2 percent) stated that they had established age cutoffs for adolescent patients because of excessive time demands of this age group (226).

A direct observation study of office-based general pediatricians found that they spent an average of 7 seconds on anticipatory guidance for adolescent patients ages 13 to 18, 37 seconds for children ages 5 to 12, and 87 seconds for older infants (223). It should be noted that the pediatricians observed in this regional study contrasted with the physicians included in the national sample because those in the regional study averaged fewer minutes for total visit time with adolescent patients (8.4 minutes). However, this study also determined that younger physicians and those in group practice were more likely to spend more time with their patients in general, and that the mean proportion of visit time spent addressing anticipatory guidance issues was greater (223).

The content of physician-provided adolescent health counseling has been studied using three different designs. A direct observation study of pediatricians documented that 88 percent of anticipatory guidance time was divided between discussion of potential organic problems (54 percent) and immunizations (34 percent). Nutritional issues accounted for 2 percent, and development accounted for 4 percent of health counseling time. Behavioral issues, sex education, and safety issues were not addressed by this sample of pediatricians (223).

A second study surveyed a national sample of pediatricians to explore their practices and attitudes toward efforts to prevent adult heart disease. It found that approximately 80 percent of pediatricians stated that they routinely discussed cigarette smoking, 78 percent discussed exercise, and 48 percent routinely discussed diet with their adolescent patients during health maintenance visits (191).

The third study that explored physicians' provision of health counseling to adolescents was a questionnaire survey of college freshmen. Its findings appear to contradict what physicians have stated to be their routine practices. The majority of this study's older adolescent respondents reported that they had received no health counseling from their physicians on the following subjects: cigarette smoking (76 percent), alcohol/drug use (80/82 percent), depression/suicide (82/90 percent), stress (69 percent), seat belt use (90 percent), contraception (81 percent), sexually transmitted diseases (79 percent), and heart disease prevention (81 percent). General nutrition counseling was not recalled by 46 percent of college freshmen. In general, internists were more likely to provide health counseling on cigarette use, substance use, and heart disease prevention than were pediatricians, and more likely than family/general practitioners to discuss cigarette use and alcohol use according to the students' recollections. Both internists and pediatricians were more likely to provide counseling on weight control and nutrition than were family/general practitioners. This study also found no correlation between the level of counseling provided and college students' reported involvement in health-compromising behaviors. The length of the doctor-patient relationship did not seem to influence the likelihood of physicians' provision of health counseling to their adolescent patients (130).

A study conducted in Canada asked adolescents ages 13 to 18 what issues they would like to discuss or have covered when they visit primary care physicians and how often the issues were actually discussed during a visit (170). The study is somewhat flawed in that both questions were asked simultaneously; the results would be more valid if the responses had been independent. In addition, the study was conducted in Canada and may not apply to the experience of U.S. adolescents. However, results of the study were consistent with previous studies that found diverging interests of health care providers and adolescents (see 170, for a review) and suggest that, at least from the adolescents' perspective, adolescents' real concerns are not being attended to by health care providers. In almost all cases, adolescents reported that discussion of issues of interest to them took place considerably less frequently than the adolescents desired.[23] As discussed in chapter 6 of this Report,[24] other studies have found that adolescents and health care providers often disagree on what are the adolescents' most important health care needs.

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[22] The range of topics that can potentially be discussed by pediatricians is quite extensive (10). An official of the American Academy of Pediatrics notes that, in practice, physicians will generally lead with only a couple of basic questions (e.g., How are things going in school? How are things at home? How are things going with friends?). If "red flags" are raised during responses to these questions, the physician will pursue with the more pointed questions listed in the American Academy of Pediatrics' guidelines (240).

Physicians' Attitudes Toward Confidential Health Care for Adolescents

Another important area of physician behavior regarding adolescent health care is patient confidentiality. Concerns about confidentiality may limit adolescents' access to needed services.[25] A study in Canada found that adolescents expressed a preference for seeking contraceptive services from family planning clinics rather than from their family physicians because they believed that their confidentiality would be broken and their parents informed (309).

Two separate studies have explored physicians' attitudes toward confidential health care for adolescents.[26] The first study was a national survey of all physician members belonging to The Society for Adolescent Medicine and a random sample of pediatricians (166). This study found that 75 percent of the surveyed physicians strongly supported patient confidentiality, especially around sexuality issues and especially for adolescents who appeared mature. Physicians who spent more than 20 percent of their practice time with adolescent patients, physicians who had formally declared their special interest in adolescents through membership in The Society for Adolescent Medicine, and younger physicians (under age 44) were all more likely to support confidential health care for adolescents (166).

A more recent study, also conducted as a mail survey of practicing physicians, was a regional investigation of physicians' attitudes toward using deception to resolve difficult ethical problems (202). The sample was composed of general practitioners, surgeons, obstetricians, gynecologists, and internists. In this study, the majority of general practitioners, surgeons, and internists (61 percent overall) stated that they would inform the mother of a pregnant 15-year-old about her daughter's pregnancy, despite the adolescent's strongly stated desire that the physician not break her confidence. The hypothetical adolescent was planning to seek termination of her pregnancy, despite her parents' disapproval. In contrast to other physician groups, the majority of obstetrician-gynecologists (63 percent) stated that they would withhold information about this patient's pregnancy from her mother. In addition, obstetrician-gynecologists were twice as likely as physicians from other groups to cite respect for confidentiality as their justification for not informing the adolescent's mother. Physician age appeared to be directly correlated with their decisions; the older the physician, the more likely he or she was to inform the parent of the adolescent's pregnancy (202). In summary, it appears as though physicians who have child- and adolescent-oriented training backgrounds, physicians experienced in reproductive health care, and younger physicians are more likely to honor adolescent patients' requests for confidential health care.

Health Care Providers' Competence in Diagnosing and Treating Adolescents' Specific Problems

How Effectively Do Physicians Recognize Adolescent Problems?

A very small body of empirical work has explored how well primary care physicians recognize specific adolescent health problems. Most studies in this area have focused on the identification of mental health and substance abuse problems. Further, most studies have been conducted by and among pediatricians.

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[23] In order by level of interest, the topics were: physical fitness, nutrition, growth, sexually transmitted diseases, contraception, acne, fear of cancer, obesity, feelings of depression, lack of confidence. The discrepancies between adolescent interest and adolescent reports of physicians' having discussed the issue are given in ch. 6, "Chronic Physical Illnesses: Prevention and Services," in Vol. II.

[24] "Chronic Physical Illnesses: Prevention and Services," in Vol. II.

[25] For further discussion, see ch. 17, "Consent and Confidentiality in Adolescent Health Care Decisionmaking," in this volume.

[26] See ch. 17, "Consent and Confidentiality in Adolescent Health Care Decisionmaking," in this volume for a discussion of professional ethical standards relevant to consent and confidentiality.

The performance of physicians practicing internal medicine or family practice is as yet untested. Little research has explored physicians' effectiveness in diagnosing or managing other problems common among adolescents.

Physicians' Identification of Emotional and Behavioral Problems—Primary care physicians appear to have difficulty in identifying children who have behavioral or emotional problems. Most of the studies cited in this section were performed on general pediatric populations or on preadolescent children. Data relevant to adolescents are specified.

The identification of mental health problems among children and adolescents is a controversial issue. A scheduled national study of the prevalence of mental health problems among children and adolescents is still in a pilot-study phase. Until that study is completed, comparisons of physician identification rates with overall prevalence rates based on epidemiologic studies should be viewed cautiously. The most recent studies suggest that between 18 and 22 percent of U.S. adolescents have mental health problems requiring treatment.[27] In contrast, a study of pediatricians' practices found that only 7.9 percent of 10- to 18-year-olds were judged to have mental health problems (103). Several other studies have found that psychiatric diagnoses made by pediatricians in prepaid group practices (including health maintenance organizations) ranked from 2 to 10 percent among the enrolled populations, and between 3 and 12 percent for patients who actually used the facility's health care services (36,66,69,124). A study of seven primary care facilities found that the proportion of children who were recognized as having behavioral, educational, or social problems varied between 5 and 15 percent by institution (265). This study appeared to use broader categories of problems than did other studies, which may explain its higher rates.

Thus, epidemiologic studies using standardized detailed assessment tools show a significantly higher proportion of children as having behavioral and emotional problems than do prevalence studies based on pediatricians' clinical assessments. However, this observation does not answer the question of how well pediatricians identify children with emotional and behavioral problems. Two separate studies specifically addressed this question. Each study compared pediatricians' reports with detailed, comprehensive psychiatric assessments that were made independently. The design of the first study was based on a psychiatrist's best estimate of a DSM-III diagnosis[28] in an individual child, synthesizing data from three sources: 1) direct interviews of parents, 2) direct interviews of children, and 3) standardized questionnaires (59). The children included in this study ranged between ages 6 and 17. Adolescent-based data were not analyzed separately, but the study sample must have contained a relatively large proportion of adolescents because its mean age was approximately 14 years. This study found very little correlation between pediatricians' reports of psychiatric and behavioral problems and assessments made by the psychiatrist and very little

Photo credit: Zacchaeus Medical Clinic, Washington, DC

Available evidence suggests that many primary care physicians do not feel comfortable treating adolescents and tend to underdiagnose certain types of problems in adolescents.

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[27] See ch. 11, "Mental Health Problems: Prevention and Treatment," in Vol. II, for a discussion of the prevalence of adolescent mental health problems.

[28] A DSM-III diagnosis is a diagnosis of a mental disorder based on the criteria put forth in the American Psychiatric Association's *Diagnostic and Statistical Manual*, 3rd edition (23a).

correlation between pediatricians' reports and independent reports by the children and their parents. In addition, the study found, pediatricians underreported both major and less serious psychiatric problems. Overall sensitivity[29] of pediatricians' reports in this study was 38 percent using the psychiatrist's synthesis and judgment as the standard. For example, pediatricians identified only 7 (35 percent) of 20 depressed children.

The second study involved children ages 7 to 11 attending pediatric primary care clinics in a health maintenance organization (71). Pediatricians' judgments about the presence or absence of emotional and behavioral problems were compared with scores of two previously validated instruments: the "Child Behavior Checklist," which is a well-known parental questionnaire that screens for social competence and behavior problems, and the "Diagnostic Interview Schedule for Children," a set of two structured psychiatric interviews for children and their parents that are designed for use in epidemiologic studies. This study found that the standardized psychiatric assessment identified twice as many children (11.8 percent) as having problems as the pediatricians did (5.6 percent). Specific examples include pediatricians identifying one-third of the children independently diagnosed as having attention deficit disorder, 35 percent of the children with conduct disorder or oppositional disorder, and 21 percent of the children with anxiety disorder and phobias. Only one of the five children diagnosed as having depression was identified by a pediatrician. Overall, pediatricians failed to identify 83 percent of children with psychiatric problems. In contrast to the findings of the previously cited study (59), this study found pediatricians' diagnoses to be highly specific; that is, they correctly identified 84 percent of the psychologically healthy children (71).

There are several reasons why primary care physicians such as pediatricians may not identify emotional and behavioral problems very effectively. Short visits are a frequently mentioned barrier to the identification of such problems (58,136). It is clearly not possible to achieve knowledge and understanding of an individual's social and psychological functioning in brief amounts of time.

A second reason for primary care physicians' tendency to underdiagnose behavioral and emotional problems may be that some adolescents and their parents do not initiate discussion of emotional and behavioral issues with their primary care physicians (58). However, a study conducted in 1969 found that 12 percent of mothers attending a pediatric outpatient department in an urban teaching hospital generated spontaneous written concerns about their children's behavior or mental health (264). The same study reported that even when these concerns were written, physicians recorded their recognition of less than half. Physicians were more likely to document their awareness of mothers' written concerns about their children's somatic problems (78 percent recognition rate) than their concerns about behavioral issues (42 percent recognition rate).

The third major reason that may explain primary care physicians' tendency to underdiagnose behavioral and emotional problems is that many primary care physicians have not had much formal education and training in this area (136).

Physicians' Identification of Substance Abuse Problems[30]—Although physicians believe that drug and alcohol use is a serious problem among adolescents and they report willingness to deal with adolescents' substance use problems, the available evidence does not suggest that physicians, as a group, are currently able to identify substance abuse problems very effectively.

A recent national study of 617 primary care practitioners conducted by the American Medical Association (AMA) found that physicians appeared willing to provide counseling for adolescents with alcohol problems, and to refer them for specialized substance abuse treatment (23). More than half (55 percent) of the surveyed physicians stated that the misuse of alcohol among adolescents is a very serious problem. Almost three-quarters (72 percent) of the responding physicians reported having seen or counseled at least one adolescent with an identified alcohol problem in their medical practices; the most common response was two adolescent patients. One-third of physicians had counseled between 1 and 5 adolescent patients for alcohol problems, and an additional 12 percent of physicians had counseled 6 to 10 adolescent patients for this problem. It should be noted that the average percentage of patients between ages 12 and 18 for this physician sample was 13.4 percent. More than one-third (36 percent) of the surveyed physicians' practices contained less than 10 percent adolescents, and only 15 percent of practices contained at least one-quarter adolescent patients. This published data set did not determine the relationship between percentage of adolescent patients in a practice and the likelihood of a physician's providing counseling for an alcohol problem. In addition, this study did not explore whether the physicians had actually independently identified adolescent patients with alcohol problems or had provided counseling for patients with previously known alcohol problems. Although this study included physicians from several different primary care specialties (family and general practice, pediatrics, internal medicine, obstetrics-gynecology), it did not categorize response by specialty.

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[29] *Sensitivity* is one measure of the validity (or accuracy) of a diagnostic or screening test: the percentage of all those who actually have the condition being tested for and who are correctly identified as positive by the test.

[30] See ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II for a discussion of the prevalence of drug and alcohol abuse among adolescents.

The large majority of physicians (73 percent) in the AMA study stated that they had initiated discussion about alcohol use with their adolescent patients; fewer physicians (57 percent) had initiated discussion concerning alcohol use with their adolescent patients' parents. Almost 90 percent of surveyed physicians (89 percent) favored including counseling and treatment for alcohol use as part of their practices. The vast majority (99 percent) of surveyed physicians stated, however, that they would not treat adolescents with a serious alcohol problem by themselves, but they would include referral to a specialized treatment program for problem drinkers.

Despite physicians' willingness to treat minor problems related to substance use and appropriately refer more serious problems, it is probable that, as a group, physicians do not identify substance abuse problems very effectively. Supporting data are based on studies conducted in teaching hospitals. Even though these studies did not include office-based physicians, it is not likely that their group performance would be better, given that practicing physicians are the products of teaching hospitals, and that physician education and training in the area of substance abuse is a recent phenomenon (110,161).

The first study was conducted at the Johns Hopkins Hospital in Baltimore (187). Although it concerned the diagnosis of alcoholism in adult patients, the study's findings probably reflect the issues relevant for adolescent patients. The purpose of this study was to determine how well physicians-in-training (i.e., residents) and physician faculty detected alcoholism in hospitalized patients. The large majority of patients were admitted to the hospital for problems other than alcoholism. The patients were screened independently for alcoholism by structured interview and questionnaire. Physicians were interviewed about individual patients to determine whether they had diagnosed any alcohol-related problems, how their diagnoses were determined, and what treatment plans had been made. It was found that house officers' and faculty physicians' detection rates varied between 0 and 66 percent depending on clinical specialty. In general, faculty physicians performed no better than their trainees, the resident physicians; in fact, the house officers (residents) of some specialty services were more successful than their faculty in identifying alcohol problems. Overall, psychiatrists performed better than other specialists; they correctly identified two-thirds of patients with alcohol-related problems. Internists successfully identified 35 to 52 percent of patients, surgeons identified only 20 to 27 percent of patients, and gynecologists were virtually unable to identify any patient as having an alcohol problem; their sensitivity was 0 to 7 percent (187).

A second study was conducted in the emergency department of an urban teaching hospital (58). This study reviewed the medical records of 346 motor vehicle accident patients to determine the surveillance of alcohol intoxication by surgical resident physicians. This study found that only 25 percent of these patients were tested for blood alcohol concentration even though current textbooks recommended routine testing of all trauma patients for alcohol use. A State law that was enacted during the course of the study allowed a hospital laboratory's analysis of patients' blood to be used to establish probable cause for drinking. This law did not affect the surgical residents' rates of determining patients' blood alcohol concentration levels. In addition, no patient was referred by these surgical residents for further evaluation or treatment of alcohol abuse (58). This study's findings of surgical residents' inattention to alcohol problems are similar to the earlier study's findings.

Two studies have attempted to assess physicians' detection of substance abuse problems in an adolescent patient population. In a study by Oelberg and

Finkelstein of the patient records of hospitalized adolescents, the majority of internal medicine and obstetric/gynecologic records contained documentation of a history of smoking and alcohol use; pediatric and surgical records did not contain such documentation (204). However, very few records from any specialty service contained information concerning illicit drug use.

In a more recent study, 54 new adolescent patients presenting for outpatient care in an urban teaching hospital's adolescent medicine program each completed a structured questionnaire designed especially to assess adolescent patients' involvement with drugs and alcohol (254). The responsible medical clinicians independently judged the likelihoods of their individual patients as having substance abuse problems. Thirty-seven percent of patients independently self-reported substance use at sufficiently high levels to be considered abusers. The sensitivity of medical providers' judgments was only 25 percent, and the positive predictive values (concordance between medical provider and patient's self-report on the presence of substance abuse) was only 46 percent, slightly worse than chance alone. In this study, as in others based on adult patient samples, medical providers greatly underestimated the presence of substance abuse problems (254).

There are several reasons for physicians' relatively poor performance in identifying substance abuse problems. First, historically, medical schools and residency training programs have not addressed the issue of substance abuse. Although this situation is changing, with both schools and individual training programs now incorporating substance abuse issues into their curricula, physicians who are already in practice will not be exposed to this body of knowledge. One study, conducted among medical students and resident physicians in 1986-87, found a strong relationship between trainees' perceived role responsibility regarding alcoholic patients, self-confidence in their skills, and their reported screening and referral practices (97). In particular, trainees with higher levels of self-confidence in their skills had enhanced perceptions of their role responsibilities for screening patients for alcoholism and for providing interventions through referral. Physician resistance to caring for patients with substance abuse problems is thought to be related to their lack of formal learning and preparation (136).

A second barrier to physician identification of substance abuse problems is related to patient attitudes. Probably a majority of patients with substance abuse problems deny that they have such a problem and resist evaluation and intervention efforts (136). Adolescents may be particularly reluctant to admit substance use to a health professional when a parent is present during the visit. One survey of 54 substance-abusing adolescents found that 46 percent responded dishonestly to a physician's questions about alcohol or drug use, often because a parent was present (96). Even well-meaning physicians, if they lack appropriate assessment skills, may not be able to identify substance abuse problems.

The third major barrier to identification of substance abuse disorders is organizational. Assessment of substance abuse disorders is time-consuming, and in general, primary care practitioners may not be adequately reimbursed for time spent with and on behalf of patients with substance abuse problems (136). In addition, it may be difficult for physicians to gain access to treatment resources for their patients.[31]

Physicians' Identification of Physical Problems—For the most part, the ability of physicians to identify physical problems in adolescents has not been studied empirically (28). An example of a group of physical problems that has received some study—albeit minimally—is dermatological problems. Additionally, one study examined how well *hospitalized* adolescents are screened for a variety of physical problems.

Primary Care Physicians' Ability To Identify Dermatological Problems—Primary care physicians' identification of dermatological problems has been studied minimally; their ability to manage such problems has not been studied at all. Dermatological problems are a leading reason for adolescent visits to physicians.[32] However, dermatologists provide care for only 37 percent of dermatological problems overall; the remainder are largely seen by primary care physicians (132).

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[31] See ch. 16, "Financial Access to Health Services," in this volume, for a discussion of financial issues in adolescents' access to substance abuse treatment and ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II, for a discussion of other issues in gaining access to substance abuse treatment services for adolescents.

[32] See ch. 6, "Chronic Physical Illnesses: Prevention and Services," in Vol. II, for a discussion of common physical problems in adolescence. Also see "Health Care of Adolescents by Office-Based Physicians: National Ambulatory Medical Care Survey" (284).

A study of 285 adult primary care providers (family and general practitioners and internists) found that, on the average, these physicians correctly identified only 54 percent of 20 commonly seen or serious dermatoses (dermatological problems) (218). The majority of these common skin problems are also seen in adolescent patients. Interestingly, acne, the dermatosis most prevalent in adolescents, was correctly identified by 94 percent of these primary care physicians (218). A similarly designed study evaluated how well pediatric residents are able to identify 20 common skin disorders (217). This study found that the residents' average score was 53 percent; level of training had little effect on test score. Again, however, a relatively high percentage of residents (68 percent) correctly identified acne (217). However, these studies do not address whether dermatological problems were identified in the context of a visit not specifically related to dermatological problems.

No empirical study has addressed how effectively primary care physicians actually manage skin problems. The documented difficulty in diagnosis may imply that management is not optimal. It is not clear how frequently primary care physicians refer patients to dermatologists or how they decide which patients should be referred. Only 7 percent of dermatologists' patients overall are referred by other physicians (132). One can infer from a readership survey of a widely circulated journal, which pediatricians receive free of charge, that pediatricians make selective referrals to dermatologists (68). A majority of pediatricians (58 percent) responded that they have referred patients for dermatological care. This same survey found that approximately half (51 percent) of pediatricians "usually" refer patients for psoriasis. In contrast, the readership survey found that patients with acne were referred only 13 percent of the time by pediatricians (68). This lower rate of referral may be consistent with pediatricians' higher rate of ability (68 percent) to diagnose acne accurately (217).

Physicians' Collection of Information on Hospitalized Adolescents—A single study examined how frequently physicians from different specialties collect complete data on hospitalized adolescent patients (204). This study found that no hospital service, including pediatrics, internal medicine, obstetrics and gynecology, and surgery, collected complete historical information or documented growth parameters consistently on their adolescent patients.[33]

Different patterns of strengths and weaknesses emerged for each specialty. The majority of records contained past medical histories and family medical histories. Pediatric records were more likely to contain perinatal, immunization, school, and social histories than were the medical records of other specialties. Only records from the obstetric/gynecologic service consistently recorded menstrual histories in female adolescents.

This study also suggests that adolescent anemia may be underdiagnosed (204). Complete blood counts were recorded for almost all patients in all specialties, so that the necessary laboratory data for a diagnosis of anemia were present. Although this study's authors did not provide the reference hematologic parameters by which they regarded anemia to be present, their personal chart review suggested that 37.6 percent of the hospitalized adolescents should have been diagnosed as anemic. However, anemia was actually documented as a problem in only 9.6 percent of the reviewed records.

How Do Health Care Professionals Perceive Their Competence To Provide Health Care to Adolescents?

Several recent studies have explored residents' and medical students' self-perceived interest and clinical efficacy in caring for adolescents. Several studies have phrased the question in terms of perceived deficiencies in training.

Self-Perceived Competence of Physicians—A 1981 study examined the perceptions of pediatric and internal medicine residents in a single teaching institution (255). Findings were reported for residents at the conclusion of their 3-year training programs. This study found that pediatric residents were more likely than internal medicine residents to consider various skills necessary to the practice of adolescent medicine as important. Furthermore, pediatric residents generally considered themselves more skilled than did internal medicine residents for this same set of tasks. When reproductive health issues were explored, however, both sets of residents were less apt to consider themselves skilled in providing specific contraceptive services (e.g., counseling, prescribing oral contraceptives, fitting patients for diaphragms, or inserting/removing intrauterine devices). The other major reproductive health issue considered by this study concerned counseling about and treatment for sexually transmitted diseases. In contrast to differences found in self-perceived contraceptive counseling skills, the large majority of both internal medicine and pediatric residents felt skilled in these two aspects of patient care for sexually transmitted diseases.

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[33] The failure to document that a topic was discussed does not necessarily indicate that the topic was not discussed (275).

This study also tapped residents' willingness to become personally involved in the evaluation of adolescent patients with specific problems (255). The majority of graduating internal medicine and pediatric residents in the study planned to become involved in adolescent patient care. However, patient age was an important determining factor. In general, pediatric residents were more likely to refer older adolescent patients (study example: age 19) for evaluation of specific problems; conversely, internal medicine residents were more likely to refer younger adolescent patients (study example: age 15) for evaluation. In addition, residents were more likely to refer adolescents who presented with psychosocial problems (study examples: contraception, alcohol abuse, parental abuse) than with medical problems.

This study concluded that pediatric residents considered themselves better prepared than internal medicine residents for the care of adolescent patients. However, both groups of residents lacked confidence in their counseling and contraceptive skills. The study's author commented that the very problems for which many adolescents seek or need care may be the problems that primary care physicians choose not to manage (255).

A similar study, conducted during 1984, surveyed all residents enrolled in a single community teaching hospital's six training programs (107). The six residency programs studied included family practice, internal medicine, pediatrics, emergency medicine, obstetrics/gynecology, and combined internal medicine/pediatrics. The majority of surveyed residents expected to have clinical practice careers. Many of this study's findings were consistent with the previously cited study's findings: Residents considered themselves relatively unskilled in the areas of sexuality, handicaps, endocrine problems, contraception, and psychosocial concerns. Residents from each training program identified specific areas of relative strength and weakness. Internal medicine residents were uncomfortable with gynecologic problems and contraception. Family practice residents, although confident about contraceptive and pregnancy issues, felt no more skilled than residents from other specialty groups in managing psychosocial issues. Emergency medicine residents assessed their skill levels as relatively high in managing adolescent crises and acute illnesses, problems that are likely to present at an emergency department. Residents in obstetrics/gynecology felt confident only for problems and issues that are classically considered within their expertise; they felt uncomfortable with medical problems and psychosocial problems other than sexual behavior and pregnancy. In contrast, pediatric residents did not feel skilled in gynecologic issues or in providing contraceptive care.

Pediatricians practicing in Los Angeles County were surveyed by mail (196). Although these pediatricians felt competent in managing general medical issues of adolescence, they rated their efficacy, comfort, and training experiences as somewhat lower for psychosocial issues, and as significantly lower for issues concerning sexual activity and pelvic examination. They were also less likely to regard these latter two areas as important to their practices. However, more than one-third (37 percent) of these pediatricians declared their need for greater expertise in gynecology and pelvic examination. In addition, 25 percent wanted more training around psychosocial problems.

The Midwestern physicians practicing general-family medicine, obstetrics/gynecology, pediatrics, internal medicine, and psychiatry who were surveyed by mail about their interest in adolescent health care were also asked about their self-perceived competence in providing care to adolescents (207). Self-perceived competence varied by specialty, with no specialty feeling competent to address all problem areas included in this study. At least 50 percent of general-family practitioners felt competent to manage 8 of the 10 service areas listed by the study, and at least 50 percent of pediatricians felt competent to manage 5 areas. Internists, obstetricians-gynecologists, and psychiatrists had significantly narrower foci of perceived self-competence. The majority of physicians from medical specialties did not perceive themselves competent in counseling. No specialty felt particularly confident about substance abuse issues, although approximately two-thirds of general-family practitioners (65 percent) and psychiatrists (68 percent) felt competent in this area. Approximately half of pediatricians (54 percent) and psychiatrists (50 percent) and only 41 percent of internists felt competent to address sexual concerns with regard to adolescents, although the large majority of general-family practitioners (89 percent) and obstetrician-gynecologists (96 percent) felt comfortable in this area. Consistent with this finding were the low levels of self-perceived expertise in family planning perceived by physicians in specialties other than general-family practice and obstetrics-gynecology. In contrast, pediatricians (75 percent) and internists (62 percent) felt more prepared to address adolescent patients with chronic illness than did general-family practitioners (54 percent).

This study also explored physicians' perceived training needs by determining their interests in specific continuing medical education topics (207). The most popular topics for hypothetical continuing medical education included substance abuse, counseling, learning problems, and eating disorders. In general, physicians desired further education in areas where they already reported self-competence. The exceptions to this observation included pediatricians and general-family practitioners. Greater proportions of pediatricians with lower self-perceived competence v. positively rated competence desired continuing education in counseling, substance abuse, and family planning. At least 30 percent of pediatricians wanted to learn more about each of the 10 service topic areas listed on the survey. Similarly, general-family practitioners who did not perceive themselves as knowledgeable in chronic illness desired more education in this area. Overall, more than 30 percent of general-family practitioners were interested in further education in 8 of the 10 listed areas. The other specialists, including internists, psychiatrists, and obstetrician-gynecologists, were more focused in their interests in continuing medical education in topics relevant to adolescent medicine (207).

Robert Blum and his colleagues have also addressed the issue of self-perceived competence among health care providers (40,41,42). A national mail survey of primary care physicians, including pediatricians, internists, and family practitioners, assessed practicing physicians' needs in adolescent care (40,41). Areas of perceived training deficit relevant to adolescent care varied by specialty. Of the 19 problem areas listed in this study, at least 50 percent of all responding physicians reported having received insufficient training in 10 areas. Eight of these 10 areas of self-perceived weaknesses pertained to psychosocial, behavioral, and mental health problems; more than 45 percent of physicians felt deficient in these areas. The large majority of internists (at least 74 percent) reported training deficiencies for all 19 areas. In contrast, greater proportions of family practitioners and pediatricians perceived having received adequate training. There were seven topic areas for which at least 50 percent of family practitioners felt insufficiently trained to handle, and similarly, eight topic areas for pediatricians. Six of the seven topic areas for family practitioners, and six of the eight topic areas for pediatricians, consisted of psychosocial, behavioral, and mental health concerns.

Despite the high rates of acknowledged deficits among these primary care physicians, relatively few expressed a desire to upgrade their skills. Overall, no more than 30 percent of physicians who had self-identified deficiencies desired to increase their proficiency in any of the 19 topic areas. Interest was particularly low for internists; between 0 and 8 percent of those with self-perceived deficiency wanted further training in any given topic relevant to adolescent care. The percentage ranges for interested pediatricians were 10 to 36 percent and for family practitioners, 7 to 42 percent. However, this study did not present data describing the overall interest of physicians in attending educational courses relevant to adolescent care.

Self-Perceived Competence of Nonphysician Health Care Providers—Less is known about the knowledge base of health care professionals who are not physicians regarding adolescent care. The same survey by Blum and his colleagues that was directed to physicians (40,41) was also sent to professionals in nursing, social work, psychology, and nutrition (40,42).

The study drew representative samples from national organizations or sections of organizations that are youth-focused. Nutritionists were the only group that was randomly selected from a general organization that did not necessarily focus on children or adolescents. However, 42 percent of responding nutritionists described the population group with which they primarily worked as being younger than age 19 (40).

In general, many health professionals, across the disciplines, felt inadequately trained to deal with critical adolescent health problems (see table 15-5) (42). More than 40 percent of the surveyed professionals in at least three of these five disciplines reported significant shortcomings in their training related to anorexia and bulimia, alcohol and drug use, homosexuality (i.e., conflict about sexual orientation), and chronic illness. In contrast with physicians, however, professionals from nutrition, psychology, and social work appeared relatively enthusiastic about enhancing their knowledge on topic areas for which they had self-identified deficiencies (40). Yet, a sizable proportion of health professionals in each discipline reported that they would not pursue continuing education or training to expand their clinical competencies (see table 15-6) (42). Physicians were the least interested among the surveyed disciplines in improving their reported training deficits (32 percent), followed by psychologists (40 percent).

What Personal Characteristics Do Effective Adolescent Health Care Professionals Have?

Many observers believe that health care professionals' ability to interact with adolescents is an extremely important factor in initiating and maintaining adolescents' use of health services. In general, however, the subject of health care professionals' ability to interact with adolescents—regardless of the specific problem that an adolescent may have—has received very little empirical investigation.

As discussed elsewhere in this Report,[34] the issue has received some attention with respect to providers' abilities to maintain adolescent involvement in treatment for sexually transmitted diseases. Attitudinal studies of adolescents that compared the importance of clinician gender with other clinician characteristics have suggested that clinician friendliness, understanding, and willingness to take their time are more important than gender (27,165). Patients who expressed satisfaction have been found to keep future medical appointments more consistently than patients who were dissatisfied (165), and clinicians who were skilled in interacting with adolescents promoted better patient compliance (27).

A study of residents explored the influences of their own adolescent risk-taking experiences and religious and political conservatism on their attitudes toward and their hypothetical professional behavior regarding adolescent patients (95). In general, more conservative residents, who also had lower risk-taking scores, rated themselves as less skilled in recognizing adolescent substance abuse, less skilled in discussing sexually transmitted diseases with an adolescent patient, and less likely to prescribe birth control pills to a sexually active adolescent without parental consent, compared with residents with higher risk-taking scores. This study emphasizes the potential important influences that individual physicians' backgrounds have on their professional behavior. These influences may become especially significant in controversial or sensitive clinical situations.

Specialized Training in Adolescent Health Care

What Is the Availability of Specialists Trained in Adolescent Health Care?

The majority of U.S. adolescents receive their health and medical care from health care providers who have not received subspecialty training in adolescent health and who have not declared special interest in adolescent health through memberships in professional organizations devoted to this age group (e.g., 83). Unfortunately, comprehensive data describing the numbers of adolescent health specialists, the nature of their training, and their activities do not exist. There are some data on clinical psychologists specializing in the care of adolescents, and those data are summarized below. Otherwise, this section is limited to a brief review of physician specialists in adolescent medicine. (Data on nurses, social workers, and nutritionists who specialize in the care of adolescents are not available.[35])

How Many Psychologists Specialize in the Clinical Care of Adolescents?—Although the number is not known, many psychologists and other

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[34] See ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services," in Vol. II.

[35] The American Board of Examiners in Clinical Social Work (ABECSW) estimates that 80 percent of their 17,000 diplomates report that they serve adolescents (43a) (adolescents are listed as one of four possible age groups in the ABECSW survey of diplomates), but the extent to which diplomates have a primary or exclusive interest in adolescent care, or special training in adolescent care, has not been determined.

Table 15-5—Number and Percentage of Surveyed Health Professionals Who Perceive Themselves To Be Insufficiently Trained To Manage Adolescents' Health Issues, by Respondents' Professional Discipline

	Respondents' professional discipline									
	Medicine (N = 352)		Nursing (N = 445)		Nutrition (N = 549)		Psychology (N = 460)		Social work (N = 403)	
Area of insufficient training	n	Percent	n	Percent	n	Percent	n	Percent	n	Percent
Growth/development problems (physical and social/psychological)	78	22.6	58	13.0	NA	NA	22	4.7	54	13.4
Obesity	60	17.0	81	18.2	104	18.9	268	58.3	NA	NA
Anorexia/bulimia	192	54.5	118	26.5	268	48.8	287	62.4	269	66.7
Pregnancy	38	10.8	90	20.2	109	19.9	236	51.3	192	47.6
Alcohol/drug abuse	134	38.1	178	40.0	294	46.3	253	55.0	182	45.1
Homosexuality	190	54.0	220	49.4	NA	NA	233	50.6	190	47.1
Family conflicts	109	31.0	122	27.4	NA	NA	30	6.5	54	13.4
Suicide risk	151	42.9	171	38.4	NA	NA	124	27.0	142	35.2
School-based learning and behavior problems	147	41.8	157	35.3	NA	NA	40	8.7	124	30.8
Chronic illness	176	50.0	167	37.5	NA	NA	296	64.3	270	67.0
Depression	142	40.3	195	43.8	NA	NA	73	15.9	118	29.3
Psychosomatic complaints	55	15.6	133	30.0	319	58.1	123	26.7	170	42.2
Delinquency	194	55.1	224	50.3	NA	NA	143	31.1	96	23.8
Sports injuries/health problems	124	35.2	188	42.2	292	53.2	NA	NA	NA	NA
Sexually transmitted diseases	56	16.0	91	20.4	NA	NA	NA	NA	225	55.8
Family planning	79	22.4	100	22.0	NA	NA	NA	NA	128	31.8

NA = Not applicable.

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Table 15-6—Number and Percentage of Surveyed Health Professionals Who Want Additional Training in Areas in Which They Reported Insufficient Training[a]

	Respondents' professional discipline							
	Medicine[a]		Nutrition[a]		Psychology[a]		Social work[a]	
Area of insufficient training	n	Percent	n	Percent	n	Percent	n	Percent
Growth/development problems (physical and social/psychological)	28	35.9	NA	NA	14	63.6	30	55.6
Obesity	20	33.3	71	68.3	82	30.1	NA	NA
Anorexia/bulimia	49	25.5	141	52.6	98	34.1	128	47.6
Pregnancy	5	20.0	48	44.0	56	23.7	46	24.0
Alcohol/drug abuse	50	37.6	130	44.2	80	31.6	108	59.3
Homosexuality	50	26.5	NA	NA	85	35.0	87	45.8
Family conflicts	42	47.7	NA	NA	20	66.1	43	79.6
Suicide risk	45	30.0	NA	NA	62	50.0	93	65.5
School-based learning and behavior problems	52	36.6	NA	NA	17	42.5	78	62.9
Chronic illness	34	19.3	NA	NA	94	31.8	77	28.5
Depression	51	36.2	NA	NA	13	31.7	85	72.0
Psychosomatic complaints	16	38.1	89	27.9	73	59.5	99	58.2
Delinquency	49	25.4	NA	NA	35	24.5	44	45.5
Sports injuries/health problems	51	38.3	182	75.2	NA	NA	NA	NA
Sexually transmitted diseases	18	32.1	NA	NA	NA	NA	93	42.3
Family planning	19	30.6	57	20.9	NA	NA	46	35.9

NA = Not applicable.

[a] For the number of surveyed professionals who reported insufficient training, see table 15-5.

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health care providers (clinical social workers, nurses, health educators, nutritionists) encounter and care for adolescents in their clinical practices, in schools, residential institutions, and other settings. The only available data on psychologists who specialize in adolescence comes from the membership files of the American Psychological Association. In 1989, 1,487 psychologists reported to the association that their primary professional interest was adolescents; this number represented 2.2 percent of the American Psychological Association's total membership and 4.4 percent of members who are clinical psychologists (24). Their interests included developmental adolescence, clinical-adolescent therapy, and clinical-juvenile delinquency.

How Many Physicians Specialize in Adolescent Medicine?—Until recently, adolescent medicine was not a certified medical subspecialty.[36] Thus, there are no definitive data on the number of physicians specializing in adolescent medicine. Nonetheless, statistics provided by The Society for Adolescent Medicine (SAM), American Academy of Pediatrics, AMA, and other membership societies are useful indicators of the number of physicians with a special interest in adolescent medicine (see table 15-7).[37] The available data make clear that the number of physicians who dedicate their practices to adolescent medicine is quite small.

SAM was established in 1968 and, as of 1989, included 1,034 members from multiple disciplines (including nonphysicians), although the vast majority (82 percent) are pediatricians (261).[38] The training backgrounds of physician members include pediatrics (84 percent), family practice (7 percent), internal medicine (5 percent), obstetrics-gynecology (3 percent), and psychiatry (1 percent) (261).

The American Academy of Pediatrics formed a Section on Adolescent Health in 1978, in response to pediatrician members' requests for a special interest group. By 1989, this section was the third largest of the academy's 32 sections for practicing pediatricians and contained 547 members, or slightly more than 2 percent of the American Academy of Pediatrics' total membership. The extent of overlap between this group and SAM is not known, but it is estimated that the vast majority (about 500) of the American Academy of Pediatrics' special section are also members of SAM (64).

Table 15-7—Estimates of the Number of Physicians Specializing in Adolescent Medicine

Source of data	Number of physicians expressing interest in adolescent medicine[a]
Primary care specialties	
Society for Adolescent Medicine 1989 membership statistics	1,034
American Academy of Pediatrics' Section on Adolescent Health 1989 membership statistics	547[b]
American Medical Association 1988 Physician Masterfile	1,420 total
Adolescent medicine is primary or secondary specialty	1,261
Adolescent medicine is third specialty	159
Other specialties	
North American Society of Pediatric and Adolescent Gynecology	370
American Society for Adolescent Psychiatry	1,500

[a] Note that estimates overlap and cannot be summed.

[b] An estimated 500 of the 547 are also members of the Society for Adolescent Medicine (64).

SOURCE: Office of Technology Assessment, 1991.

The AMA formally established adolescent medicine as a separate specialty in 1977 (33). The AMA's physician masterfile updates its information on individual physicians (including nonmembers) through a structured mail survey using a 4-year rotating cycle, so that each responding physician completes a questionnaire every 4 years. Of the almost 800,000 physicians who listed a primary or secondary specialty in the 1988 data set, only 1,261 selected adolescent medicine from the predesignated specialty categories (86). Of the 39,000 physicians who listed a third specialty, an additional

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[36] As this Report went to press, an application to formally establish adolescent medicine as a subspecialty of pediatrics was approved by the American Board of Medical Specialties (152).

[37] Specialists are physicians who have completed 1 to 5 years of additional training in a specialty area. Such training is not required for medical licensure, but physicians who have specialty training may be eligible to become certified by a specialty board. Even if they have not received specialty training or been board-certified, however, physicians may designate themselves specialists (275). In addition to offering a general certification, several boards offer certificates in *sub*specialty areas.

[38] Note also that more than four out of five physicians trained in adolescent medicine between 1974 and 1984 were pediatricians; the remainder were internists, family practitioners, or other primary care specialists (220). Most recently, of the 60 physicians in adolescent medicine fellowships in January 1990, 47 had pediatric backgrounds, 6 had completed residencies in family practice, 3 were internists, and 2 had completed combined training in internal medicine and pediatrics (121).

159 selected adolescent medicine. Overall, a total of 1,420 physicians in the AMA masterfile (0.2 percent of all U.S. physicians) declared a formal interest in adolescent medicine. Yet only about one-third (32 percent) of responding physicians practicing adolescent medicine perceived it to be their primary area of practice.

The American Academy of Child and Adolescent Psychiatry estimates that 5,000 child- and adolescent-trained psychiatrists are currently available in the United States (276). The American Society for Adolescent Psychiatry has 1,500 members, and the North American Society for Pediatric and Adolescent Gynecology has 370 members (49,298).

Although many members of the American Academy of Family Physicians and the American College of Physicians care for adolescent patients, how many actually specialize in adolescent health is unknown. Neither organization keeps track of members with a special interest in adolescent medicine (189,256). It should be noted, however, that subspecialization in any particular age group is contrary to the discipline of family practice, which emphasizes the importance of comprehensive patient and family medical care (1).

What Are the Training Opportunities in Adolescent Medicine?

Some physicians may get some general experience in adolescent health care while being trained in primary care specialties such as pediatrics, family practice, or internal medicine. Physicians who specialize in adolescent medicine receive the most intensive and advanced training in adolescent medicine as a medical subspecialty. Specialty training in psychiatry or obstetrics/gynecology may also include experience in adolescent health care.

Primary Care Training—In January 1990, the Pediatric Residency Review Committee of the Accreditation Council for Graduate Medical Education significantly expanded its requirements for pediatric residency training experience in adolescent medicine (83). Accredited pediatric residencies must now incorporate a structured adolescent medicine experience that includes health maintenance examinations, family planning, sexually transmitted diseases, and gynecology (1).[39] Experiences in chemical dependency treatment, sports medicine, health needs of incarcerated youth, and college health issues are also strongly recommended. The requirements further specify that a separate adolescent medicine clinic is desirable. Exposure to adolescent medicine must be both didactic and clinical and must take place in inpatient and outpatient settings. However, the training requirements do not specify an age range for adolescent patients. Further, a specific time duration for experience in adolescent medicine is not required.

Accredited residency programs in family practice are required to include a 4- to 5-month structured educational experience in pediatrics, but there are no specific requirements for exposure to adolescents (4). Family practice residents may take an elective in adolescent medicine in a department of pediatrics; it is not known how many actually do. A recent survey of family practice residency programs found that 40 percent of training programs included adolescence as a specific component of the curriculum (250). Of the 154 programs reporting the number of adolescent patients that a trainee followed as part of his or her "practice," more than half (54 percent) estimated 20 patients or less. Only about 40 percent of the responding family practice programs had either trainees or faculty members with specific interests in adolescent medicine, and only 6 percent of responding programs offered at least 1 month's dedicated experience in adolescent medicine (250).

Although the guidelines for accredited residency training programs in internal medicine stipulate that residents should gain experience in caring for adolescent patients, they do not call for any specific curricula in adolescent medicine nor do they specify any age range for adolescent patients or time duration for experience in adolescent medicine (3).

Subspecialty Training—The majority of physicians who devote a significant portion of their time to practicing adolescent medicine have received subspecialty fellowship training (260).[40] The first fellowship program in adolescent medicine was organized in 1956 at Children's Hospital Medical Center in Boston and since then an estimated 750 physicians have been trained in adolescent medicine (121,222). Most adolescent medicine fellowship programs accept trainees who have completed residencies in either pediatrics, internal medicine, or family practice.

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[39] A study in 1978 found that two-thirds (66 percent) of surveyed pediatricians believed their residency training had *not* prepared them adequately for the care of adolescents (16). Later, the residency experience in adolescent medicine appears to have improved, so that pediatricians who had completed their residencies after 1974 were less likely to rate their training as insufficient in adolescent medicine, compared with pediatricians who had completed their residencies during earlier years.

[40] Subspecialty training occurs after completion of a residency training program in a certified specialty. It is important to note that not all subspecialties, including adolescent medicine, are certified by the American Board of Medical Specialties.

Training opportunities in adolescent medicine are few in number and typically are located only in teaching hospitals in major metropolitan areas (261). As of January 1990, there were 39 adolescent medicine physician fellowship programs in the United States, with 60 active fellows (121).[41] The programs are small; 20 of the 39 fellowships train only one fellow at a time, and most of the others have the capacity to train only two.

Postdoctoral fellows in adolescent medicine are distributed fairly evenly by gender: 46 percent of fellows enrolled in training during 1988-89 were women.

Adolescent medicine subspecialty training programs vary in curriculum and duration. Now that adolescent medicine has been established as a formal pediatric subspecialty, programs should become more uniform. Official curriculum standards for fellowships in adolescent medicine will be established. Currently, the fellowship training guidelines published by SAM are voluntary and no one knows how many programs adhere to them. SAM recommends that 1-year adolescent fellowship programs emphasize clinical training; 2-year programs provide additional skills in clinical research and/or program administration in adolescent health care; and 3-year programs enable the fellow to function as an independent investigator (258). It is, therefore, not surprising to find that physicians who have completed 1-year training programs are more likely to be in full-time private practice with less time devoted solely to adolescent medicine (220,221). Surveys of physicians who have completed adolescent medicine fellowship programs have found that 2-year fellows are significantly more likely than others to have full-time academic careers and to devote 75 to 100 percent of their time to adolescent medicine (both academic and clinical) (220,221).

Eight basic areas of skill and knowledge are emphasized by the SAM program training guidelines: interviewing skills, growth and development, sexuality, medical problems, psychological and social problems, preventive health care, academic and research skills, and management and health care delivery (258). The guidelines also stress that training programs embody a team approach which includes at a minimum a social worker, mental health specialist, and nurse—all with established experience in adolescent health care. A psychologist and/or psychiatrist; nutritionist, nurse practitioner and/or physicians' assistant; teachers; and physical, recreational, and occupational therapists are also recommended.

Photo credit: © Peter Byron, Morris Plains, NJ

Training opportunities in adolescent medicine are few in number and typically are found only in teaching hospitals in major metropolitan areas.

The duration of adolescent medicine subspecialty training has increased since the fellowships were first established. Only 22 percent of those who completed their training between 1974 and 1979 were in 2-year programs; the vast majority of trainees, during that period, participated in 1-year fellowships (221). From 1979 through 1984, the proportion of 2-year trainees increased to more than one-third (34 percent) (221). The trend toward longer training continues; in 1984, 35 percent of all programs offered 1-year fellowships; by 1990, 59 percent of all fellowships required 2 years of training and only 8 percent allowed 1 year.

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[41] In addition, there were two programs in Canada and one in Puerto Rico.

What Do Physicians Trained in Adolescent Medicine Do?

Limited information is available concerning the current activities of adolescent medicine specialists. Recent data from a 1989 SAM membership survey are useful, but, because it is chiefly pediatricians who have elected to become members of SAM, SAM data principally reflect the activities of pediatricians specializing in adolescent medicine and do not include the family practitioners, internists, psychiatrists, and others with a special interest in adolescent health. Ninety percent of the respondents to the 1989 SAM membership survey were physicians, and more than half (57 percent) of the responding physician members had completed a formal postdoctoral fellowship in adolescent medicine (260). Overall, SAM members (including nonphysicians) tend to be involved in academic medicine. That is, more than one-third (37 percent) of SAM's members have a full-time appointment to a university or medical school, and an additional 44 percent carry an adjunct or clinical appointment. Only 30 percent of the 1989 SAM survey respondents devote all of their time to adolescent medicine activities, including time involved in clinical work, teaching, research, and administrative responsibilities.

The SAM survey also found that adolescent medicine specialists were more likely to spend their time in outpatient or office-based patient care than in inpatient care. Eighty-seven percent of respondents spent less than 25 percent of their time on inpatient care (260).

How Effective Is Specialized Training in Adolescent Health Care?

Only two published studies have attempted to evaluate the effectiveness of specialized training in adolescent medicine. Both have methodological limitations. Only one included an objective evaluation of physicians' skills (197). Neither included ratings by adolescent patients of physicians' skills.[42]

Neinstein and his colleagues assessed the impact of an adolescent medicine rotation on the attitudes and skills of advanced medical students and pediatric residents (197). Important findings included an increased liking of adolescents by residents as well as significantly improved pelvic examination skills by trainees at the conclusion of the rotation, compared with prerotation scores, and with scores of residents who did not select the rotation. These changes appeared to persist across a 1-year time interval. The validity of this study's findings may have been limited by a potential subject-selection bias. The adolescent medicine rotation was not required, and residents were not assigned to it on a random basis; residents could select it or another rotation. The majority of residents, however, did select the rotation. In addition, residents served as their own controls and had two measurement points prior to starting the rotation in adolescent medicine. If this study's findings are valid, it appears that rotational experience through an adolescent medicine service can help both to modify trainees' attitudes about adolescents and to enhance their clinical skills.

Chastain and colleagues' more recent study of a national sample of pediatricians compared pediatricians who had formally declared their interest in adolescent medicine through membership in the American Academy of Pediatrics Section on Adolescent Health with other randomly selected pediatricians (60). Twenty-nine percent of the group with formally declared interest in adolescent medicine had elected to receive advanced training in adolescent medicine through postdoctoral fellowships; overall, however, 50 percent of this group had undergone formal training in adolescent medicine at some point in their careers. About 30 percent of the randomly selected pediatricians had also received formal exposure to adolescent medicine teaching, usually through residency experience. As would be expected, the pediatricians with a formally declared interest in adolescent medicine rated their self-perceived skills across the spectrum of common adolescent problems as significantly higher than the other pediatricians did. These differences were especially pronounced in their self-perceived abilities to diagnose and manage psychosocial problems, substance abuse, eating disorders, and sexually transmitted infections; to perform pelvic examinations; and to provide contraceptive counseling.

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[42] In a previous study, OTA found that patients' ratings were a valid indicator of some aspects of quality of care (275).

When Chastain and colleagues examined training issues across time, the following findings emerged (60). Even though the percentage of pediatricians who have received formal training in adolescent medicine has increased over the past two decades, only slightly more than one-third (35 percent) of all pediatricians participating in the survey had received formal instruction in adolescent medicine as part of their residency during the decade 1976 to 1985, 7 years of which followed the Task Force on Pediatric Education's 1978 recommendation that all pediatric training routinely include training in adolescent medicine (16). Among pediatricians without a designated formal interest in adolescent medicine, those who had graduated from medical school since 1976 felt less adequately trained than did those who had graduated during the preceding decade, 1966 to 1975. Each successive cohort of these more recent graduates, however, felt more competent than did their older colleagues in several classical areas of adolescent medicine, including substance abuse, sexually transmitted diseases, pelvic examinations, and contraceptive counseling. However, the trend of heightened self-perceived efficacy for more recent pediatric graduates was not sustained for some content areas of adolescent medicine, including general medical problems, general psychosocial problems, sports medicine and orthopedic problems, and eating disorders (60).

What Is the Federal Government's Role in Support of Training in Adolescent Health Care?

The Federal Government began to support interdisciplinary training programs in adolescent health in 1968, but its role in training and education for adolescent health care specialists has been very limited. The Bureau of Maternal and Child Health in the Health Resources and Services Administration of DHHS currently funds six interdisciplinary training programs in adolescent health, a reduction from nine programs in fiscal year 1981 (212). The programs are located in metropolitan medical centers in Baltimore, Birmingham (Alabama), Cincinnati, Minneapolis, Seattle, and San Francisco. The programs are noteworthy for their multidisciplinary and comprehensive approaches to training; trainees include not only physicians but also psychologists, social workers, nurses, nutritionists, and others. From 1979 through 1990, these programs trained 625 individuals. Total funding for the programs was $1.8 million in 1990 and has not changed substantially in the last 5 years (see table 15-8) (212).

Table 15-8—Federal Funding for Interdisciplinary Training Programs in Adolescent Health, Fiscal Years 1986-90

Fiscal year	Total funding
1986	$1,644,000
1987	1,677,000
1988	1,700,000
1989	1,776,000
1990	1,779,000

SOURCE: J. Papai, Chief, Research and Training Branch, Bureau of Maternal and Child Health, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services, Rockville, MD, Sept. 16, 1990.

In general, little is known about past participants in the federally funded interdisciplinary programs and the role the trainees eventually play in providing health care to adolescents. A 1987-88 survey of trainees from these programs found that most (85 percent) were employed in adolescent health services in settings that included universities (26 percent), hospitals (24 percent), self-employment (8 percent), social services agencies (8 percent), mental health agencies (8 percent), and public health departments and community health programs (13 percent) (258).[43] Most graduates were employed in the States in which they were trained.

There has been no explicit Federal support of training in adolescent health for health professionals, such as family practitioners, pediatricians, internists, psychologists, nurse practitioners, and others, who are already actively involved in adolescent health care and who may seek advanced training.

Innovations in the Delivery of Health and Related Services to Adolescents

Efforts to improve the delivery of health and related services to adolescents have spawned several innovations. One innovation is comprehensive health centers for adolescents. Comprehensive health centers for adolescents take a variety of organizational forms, ranging from community-based adolescent health care clinics to school-linked health centers (SLHCs). Another innovation, which might be considered an alternative to the provision of comprehensive services at a single site, is to use case management and other methods to integrate services in the community for adolescents. A third innovation, and one used by OTA in the preparation of this assessment, is for organizations involved in the delivery of services to seek adolescents' advice on how to become more responsive to their needs.

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[43] This survey was conducted in 1987 and 1988 by the Division of Adolescent Medicine, Child Development Center, University of Washington and was targeted to 283 individuals who had completed their training in the previous 5 years. The response rate was 55 percent.

Comprehensive Health Centers for Adolescents

Comprehensive health centers for adolescents typically offer adolescents a variety of health and related services in a single site and have a team of staff members who are knowledgeable about and committed to helping adolescents (192). Such centers, which take a variety of forms described further below, are an alternative to the traditional model of health care delivery that typically takes place in physicians' offices.

Many of the comprehensive programs described below were developed in response to specific communities' needs, so their organizational structures and the services they offer vary widely. Some of the programs developed their structural foundations de novo (independently); others incorporated their services into the functioning of existing organizations.

Nonetheless, each described program is responsive to the specific needs of adolescents (e.g., for free care or use of sliding-fee scales, evening and weekend hours of operation, and confidentiality of services).[44]

Staff members who work in comprehensive health programs for adolescents generally choose to work there because they are committed to and enjoy helping adolescents. They are knowledgeable about adolescent development, behavior, and health and social problems. They frequently perceive themselves as advocates for their adolescent clients and may actually serve as formal case managers to work together with individual adolescents to coordinate their programs of care (292). This set of personal attributes of staff members may be one of the most cogent characteristics that separates comprehensive care programs from more traditional health services.

Photo credit: Katherine Criss, New York, NY

Comprehensive health centers for adolescents attempt to provide services that address the range of problems many adolescents face. Such services include care for acute physical illnesses, general medical exams, reproductive health care, mental health counseling, family counseling, vocational training, recreational opportunity, and child care services.

Very little formal evaluation of comprehensive care programs for adolescents has been conducted. Although the staff who operate these programs are convinced that their approaches are successful, limited funding, budgetary constraints, and other factors (e.g., diversity of mission) have precluded objective assessments of how effectively comprehensive health centers for adolescents are accomplishing their missions. More than a decade ago, the Institute of Medicine's Conference on Adolescent Behavior and Health urged that model programs be evaluated because the assumptions that have been made about preferred program structure are not grounded in empirical data (192). Impressions of highly visible programs may be regarded as documented fact, so that opportunities may be missed to determine which approaches work most effectively for different groups of adolescents.

Most types of comprehensive health care programs for adolescents share the same problem of survival: financial support for these programs is frequently difficult to secure, and finding sources of income and funding is an ongoing challenge. In general, hospital-based programs supported by teaching hospitals are an exception to concerns about a stable source of funding. As discussed further below, however, hospital-based programs face other problems that may impede the delivery of appropriate care to adolescents.

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[44] Financial barriers that impede adolescents' access to health services are discussed in ch. 16, "Financial Access to Health Services," in this volume. Laws pertaining to consent and confidentiality are discussed in ch. 17, "Consent and Confidentiality in Adolescent Health Care Decisionmaking," in this volume.

The comprehensive programs described below include adolescent health care clinics, a free clinic, a multiservice center, and SLHCs. The programs described are examples of more widespread models of innovative attempts to deliver health and related services to adolescents. In general, little information is available concerning similar programs that have been established in various communities across the United States. The number of such programs is known to be quite low, however.

Adolescent Health Care Clinics

Some hospitals, at least one health maintenance organization (HMO), and several groups of physicians acting on their own at the request of their community have established programs of medical care specifically for adolescents. The precise number of adolescent health care clinics of this type is not known. Hospital-based adolescent health care clinics are more widespread than programs initiated by groups of physicians, and hospitals with residency training programs are probably more likely to have developed such programs than hospitals without residency programs. The HMO-based and community-based adolescent health care clinics were initiated by faculty or graduates of nearby adolescent medicine training programs. In addition to providing clinical services, many of the hospital-based programs also serve as training sites for young physicians (176). Given the fact that teaching hospitals and their affiliated community health centers are frequently located in socioeconomically depressed neighborhoods, it is likely that a large proportion of adolescents who receive their health and medical care from such programs come from poor or near-poor families.[45]

There is no formal prototype for adolescent health care clinics. The majority of hospital-, HMO-, and community-based adolescent health care clinics, however, probably conform to the following general description:

- They are able to provide primary and secondary level care for adolescents with a variety of problems.
- They have a nuclear cadre of staff organized by a physician who specializes in the field of adolescent medicine and who is likely to hold a faculty appointment at a local medical school.
- They schedule adolescents' visits for a broad array of concerns, usually by appointment.
- Although they may use a "team" approach, a physician or nurse practitioner (working under a physician's supervision) is the focal provider, directs management of the patients' needs, and decides when referral resources are indicated.
- The focus of these programs, given their institutional locations and the source of their leadership, is primarily on adolescents' physical health, but the programs also attempt to identify and to provide intervention for adolescents with mental health problems. Identification of adolescents at risk for mental health problems is usually accomplished through screening. That is, a psychosocial profile is completed for every patient seen for the first time, regardless of the presenting problem. This screening may take place by interview or by questionnaire. The majority of programs have developed independent strategies to conduct these assessments. Screening interviews may be done by the primary medical clinician (physician or nurse practitioner), a nurse who coordinates the program, or a social worker. Depending on the issues that are disclosed by patients or their families, the physician or nurse practitioner may decide to ask other professional personnel to become involved in the care of an individual patient, depending on institutional resources. For example, a patient could be referred to a mental health professional (psychiatrist, psychologist, or clinical social worker), a substance abuse counselor, a vocational counselor, or a nutritionist.
- There are usually close working relationships with other medical and surgical subspecialty programs, so that adolescents can easily be referred for specific problems that may require assessment or management that is beyond the purview of an adolescent medicine practitioner.

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[45] For a discussion of the health problems of adolescents living in poor and near-poor families, see ch. 18, "Issues in the Delivery of Services to Selected Groups of Adolescents," in this volume.

- These programs may also have ties with other agencies, so that occasional patients may be referred to independent institutions, especially if internal resources (e.g., mental health resources) are limited.

Although no programmatic data are available, it is suspected that the majority of hospital- and community-based adolescent health care clinics, although they encourage parental involvement, provide confidential care to adolescents for their reproductive health needs. The costs for such confidential services may be compensated by public moneys (e.g., family planning funds under Title X of the Public Health Service Act, Medicaid funds, and local revenues), or may be borne by a larger institution that is committed to providing a full array of adolescent-oriented services. Some institutions arrange for their adolescent patients to pay for their own care using a sliding-scale fee structure.

Issues Concerning Hospital-Based Adolescent Health Care Clinics—When evaluating the effectiveness of most of the adolescent health care clinics set in the organizational structure of much larger institutions, it is important to bear in mind three major issues. One issue is that adolescents may have limited access to these programs. Hospital-based clinics are frequently located in inner-city areas that require skill in negotiating a city's public transportation system or access to an automobile. Adolescents and families of adolescents who live in more socially prosperous areas may be reluctant to use health care facilities that are known to serve impoverished populations or are in areas perceived as unsafe. Access may also be limited by a program's placement within a large complex of buildings. Finding one's way in a hospital can be intimidating. The registration process for institution-bound adolescent health care programs may be constrained by the rules of the larger institution and may not be "user-friendly." Thus, for example, an institution may not permit appointments to be scheduled in the late afternoon or early evening, times that are desirable for adolescent patients to prevent interference with school attendance. The institution may require that all patients register for their clinical care in a centralized area, prior to proceeding to patient care areas. In addition to the potential for time spent waiting in line, such a practice may violate standards for discreet provision of confidential care for sensitive health care problems. Adolescents may be required to disclose the purpose for their visits in front of other patients who have also been waiting in line. Such internal bureaucratic obstacles may in fact limit adolescents' perceived access to these specialized programs.

A second issue confronting hospital-based adolescent health care clinics is related to their mission to provide training to young professionals such as medical students, resident physicians, and nursing, psychology, and social work students. The goals of teaching trainees how to engage and work with adolescent patients and how to evaluate and manage adolescents' health and medical problems are extremely important. It is difficult for clinicians to develop these skills without practical experience. There is inherent tension, however, between the two goals of providing comprehensive yet efficient evaluation and treatment services, and teaching trainees. Overall, less experienced physicians and medical students are not able to work as quickly as experienced physicians. In addition, trainees require individual supervision for each patient that they see, during the time of the actual visits. These facts may mean that patient flow is apt to be slower for less experienced clinicians. In addition, continuity of patient care may be compromised in a teaching setting. That is, consistent clinical care across time for an individual patient (longitudinality of care) is difficult to arrange when a physician trainee is assigned to see a patient at a particular visit. In general, residents and medical students may be assigned to an adolescent health care clinic for one to two sessions, or for no longer than a month's block of time, before they are rotated to a different clinical experience. Although no known study has measured actual quality of interpersonal interaction between provider and adolescent patient, or overall quality of patient care vis-à-vis clinician's experience level, it is hypothesized that clinicians who are more experienced in working with adolescent patients perform better than do less experienced clinicians.

One measure of quality of the interaction between adolescent patients and clinician is based on patient satisfaction with the visit. A small study conducted in an adolescent health care clinic found that 75 percent of surveyed adolescent patients who had been seen by a senior physician trainee (postdoctoral fellow in adolescent medicine) were satisfied with their visits, and that only 39 percent of patients who have been seen by a resident or medical student were satisfied (165). This finding suggests that adolescent patient care programs in teaching institutions need to develop interactional strategies that help to compensate for trainees' weaknesses during the learning process. It also suggests that more attention should be focused on developing structured curricula that can teach trainees the interactional and knowledge-based skills that are essential for working with adolescents.

A final issue that concerns hospital-based adolescent health care clinics is evidence for their effectiveness. How successful are such clinics in identifying adolescents' problems, in providing interventions, and in improving the health status of their adolescent patients? Relatively little information is available to answer these questions. Recently, however, formal evaluation of a foundation-supported national demonstration program has explored these issues.

In 1982, the Robert Wood Johnson Foundation awarded twenty 4-year grants to teaching hospitals working in concert with 54 community-based agencies as part of its Program To Consolidate Health Services for High-Risk Young People (84,157,158, 267). The overall goal of this national program was to improve the health status of adolescents and young adults who lived in communities served by the individual funded projects. The four program objectives were as follows: 1) to increase health services to youth at risk for serious socioeconomic and medical problems, 2) to train health professionals in the care of youth, 3) to consolidate health services into comprehensive care centers, and 4) to secure long-term financial support for adolescent health services (157,158). Formal evaluation of this national program consisted of a longitudinal (two-wave) survey conducted over a 12-month interval of a cohort of youths receiving clinical services from seven of the funded sites and from three that included adolescents as part of their service populations but offered neither specialized services for this age group nor training programs in adolescent medicine. The funded and nonfunded clinics were similar in that they were all located in major public medical centers in their respective cities and were accessible to indigent patients (84).

Overall, more than 2,000 adolescent 13- to 18-year-old patients were interviewed twice and had their medical records reviewed as part of the evaluation process (84,267). The adolescents served by these clinical programs were at risk for serious health and behavior problems, as documented during the first wave of interviews. For example, 23 percent had a chronic illness, 79 percent were sexually active, 47 percent of interviewed adolescent females had been pregnant, 20 percent of the patients had had significant recent depressive symptoms, 25 percent engaged in illicit substance use, and 26 percent had been in physical fights (267).

Two important findings emerged from this evaluation (84). One was that adolescents attending the funded clinical service programs that were specifically geared toward adolescents were significantly more likely to disclose behavioral and lifestyle problems to their clinical providers than were adolescents attending the comparison programs (84). Consequently, larger proportions of adolescents attending the specialized adolescent programs received care (usually on site, but occasionally through referral) for these specific problems than did adolescents attending the comparison programs. In general, the funded adolescent health care programs demonstrated more extensive documentation of health problems, including behavioral and lifestyle concerns, than did the general programs. However, adolescents in both funded and nonfunded clinics were more likely to inform their medical providers of clear-cut medical problems (e.g., asthma, injury, sexually transmitted diseases) and of need for contraception than of other behavioral and lifestyle problems.

A second important finding of this evaluation was that despite their better identification and treatment capabilities for adolescent problems, the funded adolescent health care programs were not able to effect greater improvement in selected health problems, including persistent depressive symptoms, unmet contraceptive needs, and heavy alcohol or drug use, than the comparison programs (84). At the time of their second interviews, relatively similar smaller percentages of adolescents attending each type of program reported having depressive symptoms and unmet contraceptive needs than reported these problems at their initial interviews. Regardless of program type, however, virtually no changes in self-reported heavy alcohol or drug use occurred across the year interval between interviews (84).

Earls and his colleagues have suggested three reasons for the failure of the specialized adolescent-oriented programs to demonstrate differences in health outcomes for adolescents. First, the followup period of 12 months may have been too short an interval. Second, more time may be needed to test the impact of specialized primary health care for adolescents, given the newness of this field. Third, it may be inherently difficult for medical clinics alone to improve the behavioral and lifestyle problems of adolescents who attend these clinical programs because the adolescents' difficulties are so deeply embedded in the socioeconomic contexts of their environments (84).

It is a useful exercise to discuss adolescent health care clinics in the context of the attributes outlined by Schorr in her discussion of "interventions that work" for high-risk adolescents (246). Schorr based her conclusions about the nature of successful interventions on case studies of selected intervention programs. In Schorr's view, successful intervention programs offer a broad spectrum of services, cross traditional professional and bureaucratic boundaries, and remain flexible in approaches to problem solving. Successful programs also view the adolescent in the context of family, and the family in the context of its environment. In addition to their professional skills, staff members affiliated with successful programs possess commitment to and caring and respect for their clients. Structurally, successful programs' services are coherent and easy to use. Such programs attempt to reduce the possible barriers that clients may face in attempting to utilize offered services. If necessary, program staff circumvent traditional professional and bureaucratic limitations, in order to meet the needs of their clients. Schorr summarized the necessary characteristics of successful intervention programs as intensity and comprehensiveness of services, and flexibility and respectful commitment by staff (246).

Many adolescent health care clinics situated in teaching or community hospitals certainly strive to attain many of the functions and characteristics that Schorr outlined. Overall, their professional staff could be described as skilled and committed. Trainees who rotate through these programs as part of their learning experiences, however, may lack either the necessary background knowledge or the commitment to and caring about adolescents that appear so important to a successful program. Clinic staff may attempt to compensate for their trainees' weaknesses, but this issue requires continuous monitoring. It is possible that hospital-based adolescent health care clinics are not able to provide sufficient breadth or intensity of services for their patients, no matter how hard they try, given their structural limitations. In general, they operate on the campuses of large institutions. Patients may be seen for medical issues on a regular basis on site; although quarterly visits would not be considered unusual, relatively few adolescents are seen by medical clinicians as frequently as every week or every month on an ongoing basis. Mental health professionals may establish weekly or even twice weekly appointments with their adolescent clients. However, neither the medical nor the mental health interventions may provide adequate intensity of service for certain adolescents. After all, 2 hours a week of professional time, no matter how skilled, cannot realistically be expected to countermand the influences of the events taking place in the remaining 166 hours of the week of an adolescent who is experiencing major behavioral and lifestyle problems. Finally, adolescent health care clinics usually function in the context of the bureaucracy of a larger institution. Although program staff may successfully negotiate with the institution's administration for policies that lower barriers to care (e.g., issues requiring the need for parental consent and payment for services), they are still frequently constrained by institutional rules, and by the large imposing buildings in which their clinical space is often located.

Community- and HMO-Based Adolescent Health Care Clinics—In some suburban communities, health care professionals trained in adolescent health care have developed special adolescent health care centers that are not formally affiliated with hospitals. Two examples are described in box 15-A. One center was developed in response to community concerns by adolescent medicine faculty physicians based at a teaching hospital in a suburban Long Island, New York, community (92,175). Another, the Teen and Young Adult Health Center, is part of the Kaiser Permanente HMO, and is situated at Kaiser's Granada Hills, California, location (135,146).

Free Clinics

Free clinics developed approximately two decades ago in this country in response to the needs of substance-using youth, many of whom were alienated from society at large and were unable or unwilling to receive medical care from traditional sources. Free clinics do not set eligibility requirements or charge fees for service, although they do accept donations from their clients. In general, free clinic services are provided by volunteers, with agency activities coordinated by a core of paid staff.

Box 15-A—A Community-Based and an HMO-Based Adolescent Health Care Clinic

In recent years, health care professionals trained in adolescent health care have developed adolescent health care programs that are *not* formally affiliated with hospitals. Two examples, both in suburban communities, are described below.

A Community-Based Adolescent Health Care Clinic in Long Island, NY

A comprehensive adolescent health care service that was developed for a suburban Long Island community by adolescent medicine faculty physicians based at a teaching hospital is described by Fisher, Marks, and Trieller (92). This program was established in 1980 in response to the request of a group of civic leaders living in a middle- to upper-class suburb. A survey of the community's junior and senior high school students was conducted as part of program planning. In general, although significant proportions of students disclosed regular illicit substance use (20 percent), sexual activity (24 percent), and concern about a self-perceived weight problem (38 percent), very few students (1 percent, 4 percent, and 10 percent, respectively) had actually sought care for these matters. Despite their ready access to private office-based physicians (90 percent had a specific doctor, and 93 percent had visited a doctor within the previous year), the majority of students stated that they would not choose to use a private physician for reproductive health care, substance abuse, or emotional problems, and furthermore, that they would not be willing to seek care for these problems with their parents' knowledge (175). Thus, even in a middle-class community that is well-supplied by private physicians, adolescents perceived the need for an alternative resource for their reproductive health care and other sensitive problems.

The Long Island community-based adolescent health clinic is located in a building shared with a substance abuse counseling agency. It is staffed by a nurse coordinator (who also is a master's prepared counselor), and pediatricians specializing in adolescent medicine. The nurse coordinator performs basic medical and psychological counseling, as well as program administration and outreach. Although confidential health care is provided for sexuality-related matters, adolescents younger than age 18 must have parental consent in order to receive care for other problems.

Funding for the program comes primarily from the New York State Department of Health but also from local funding sources. Although adolescent patients were seen free of charge during the first 2 years of the program's operation (92), fees were later instituted at the request of the State funding agency after a survey of registered patients was conducted. The majority of these patients affirmed that they would be personally able and willing to pay for services without help from their parents (93). From 1982 until recently, adolescents were charged no more than $25.00 for an initial visit and $15.00 for a followup visit. Patients were asked to pay as much as they could at the times of their visits; no bills were sent home. The overall collection rate, based on total accrued charges, has been 73 percent. Only 16 percent of patients have not been able to pay even a portion of their bills (92). Recently, however, a cut in State funding has caused the program to curtail its operations to approximately half-time for the nurse coordinator and to 6 hours a week of physician time. In addition, the program has raised its fee schedule to $40.00 for a first visit and $25.00 for a followup visit (91a). No information is available concerning the effect of the increased fees on collection rates.

Eighty-two percent of the first 1,000 adolescents and young adults who registered for clinical care over the first 6 years of the program's operation were female. Almost three-quarters (72 percent) of the initial visits by adolescents residing in this middle-class suburban community were for reproductive health care, including contraception, pregnancy determination, and sexually transmitted infections. Over time, 67 percent were for reproductive health care. An additional 27 percent of visits were for other medical problems and for preventive care (e.g., immunizations, nutrition concerns, dermatologic and orthopedic problems). Only 6 percent of visits were for emotional concerns or substance abuse (92), despite the overall higher community prevalence rates of these problems that had been reported in the student survey preceding the opening of the program (175). Data reported from the Long Island program indicate that it has filled a void in the reproductive health care needs of adolescents.

The Kaiser Permanente Teen and Young Adult Health Center in Granda Hills, CA

The philosophy of the Kaiser Teen and Young Adult Health Center is based on that of the adolescent medicine program in the Children's Hospital Medical Center in Los Angeles (147). The Kaiser Teen and Young Adult Center attempts to have its multidisciplinary staff, many of whom have been specifically trained to work with adolescents, work in an interdisciplinary manner to meet the diverse needs of their adolescent clients. An innovative feature

Continued on next page

Box 15-A—A Community-Based and an HMO-Based Adolescent Health Care Clinic—Continued

of the Teen and Young Adult Health Centers' approach is the use of a team of "Teen Advisors." The rationale for having a special adolescent program within the HMO is to deliver health services to adolescents in a proactive and preventive, rather than a reactive, manner (146). In that spirit, the Center also produces and distributes its own newsletter, *The Kaiser Advisor*.

Staff and Services—The Center staff consists of a multidisciplinary team of professionals, including doctors in adolescent medicine and obstetrics-gynecology, health educators, a part-time social worker, a part-time psychiatrist, and a full-time project coordinator. Adolescents served at the Center are interviewed by their health care providers to identify potential or existing problems of depression, suicide, unwanted pregnancy, substance abuse, eating disorders, and other problems. In addition to this comprehensive psychosocial assessment, the Center provides comprehensive health services, which they have defined to include:

- Primary medical care (general health care; routine physicals and health assessment; treatment for acute and chronic illnesses; routine gynecological care; family planning services; pregnancy testing, diagnosis and referral; STD [sexually transmitted disease] diagnosis and treatment; contraceptive decisionmaking and education);
- Obstetrical care for adolescents (prenatal care, postpartum care, prenatal education, childbirth classes, parenting classes, nutrition counseling, and social services assistance and counseling);
- Health education services (printed materials, audio-visual programs, interactive health education computer programs, other group and individual health educational activities); and
- Social and psychological services (counseling and education regarding grief, family problems, substance abuse, sexual concerns, relationships, pregnancy, depression, and low self-esteem) (146).

In order to help expand the network of referrals to and from the Center and coordinate services with other departments, the Center project coordinator and physicians hold outreach meetings with other Kaiser Permanente departments on an ongoing basis (146)

Teen Advisors—The "Teen Advisors" are a group of volunteers, ages 15 to 20, who meet regularly at the Center, and attempt to help the Center better serve its adolescent clients by acting as a sounding board for the Center staff. The Teen Advisors review films and educational materials, and advise the Center's staff on how to work effectively with teenagers (134,135).

Program Effectiveness—No information on the effectiveness of Kaiser's Teen and Young Adult Health Center has yet been published, but an evaluation to determine "if the current Center model provides cost-effective, comprehensive physical and psychosocial health care services to adolescents and young adults in a manner that fulfills their needs and expectations, maintains and enhances their health, and encourages them to continue as health plan members in the future" (146) is under way.

SOURCE: Office of Technology Assessment, 1991.

Today, it is estimated that roughly 80 free clinics exist across the United States (112). Such clinics are more likely to be found on the west coast than in the Northeast or Midwest. Because free clinics developed in response to the needs of their home communities, they tend to serve different ethnic populations. For example, free clinics in the Southwest tend to be oriented toward Hispanic groups, and free clinics in some parts of California are apt to serve Southeast Asian refugees. In general, free clinics can offer only a finite range of health services, given their budget and staffing constraints. They can offer a relatively fast and partial solution to a community's otherwise unmet health care needs, but the directors of free clinics do not view them as being able to provide comprehensive solutions to their communities' health care problems (see box 15-B).

Little published information is available that describes the characteristics of adolescents who use free clinics. Also, very few published studies have compared the characteristics of adolescents who use free clinics with those who use other sites for their health and medical care.

Multiservice Centers That Offer Comprehensive Health and Other Services to Adolescents

Multiservice centers for adolescents operate on a model of adolescent health care delivery that recognizes adolescents' broad and varying need for services beyond traditional medical care. One multi-

Box 15-B—The Free Medical Clinic of Greater Cleveland

The Free Medical Clinic of Greater Cleveland is the third largest free clinic in the country in terms of budget and patient flow. The Free Clinic opened in 1970 to provide services to patients of all ages. Thus, many of its services are available to patients other than adolescents. In 1987, the Free Clinic provided medical services to almost 14,000 people. Visits by adolescents accounted for more than a quarter (29 percent) of all patient visits. More than 75 percent of all adolescent visits for medical services were for contraception, pregnancy testing, and treatment for sexually transmitted diseases (STDs). In 1989, the Free Clinic joined with a large tertiary care facility to establish an adolescent clinic. This and other Free Clinic services used by adolescents are described further below.

Overview—Since 1970, the Free Clinic has offered acute ambulatory medical care and drug and mental health treatment to patients of all ages. These two programs were enhanced by a hot line and a patient advocacy service that helped to direct patients to other community resources if the Free Clinic was unable to provide direct assistance. Several other programs were added over the next 7 years: an emergency dental service, a runaway shelter, a hypertension clinic, and a legal service. Recently, the Free Clinic established an anonymous human immunodeficiency virus (HIV) testing program and a medical monitoring project, which provides long-term continuity of care for individuals who are HIV-positive but lack clinically apparent symptoms.

The Free Clinic owns its current physical facilities. Five years after it opened, the Free Clinic was evicted from its original site and moved to its current location at the border of the cities of Cleveland and East Cleveland. The clinic's current location is close to the campus of Case Western Reserve University, Cleveland's largest private university. Several years after moving to its present location, the Free Clinic was able to purchase and to renovate its building and facilities through a grant based on a 9:1 State-to-private match from the State of Ohio.

Services Used by Adolescents—In the fall of 1989, the Free Clinic established an *adolescent clinic* in partnership with Rainbow Babies and Children's Hospital, a large tertiary care facility located approximately 1 mile from the clinic. Physician staffing is provided by the hospital, and the Free Clinic supplies the physical space, staff coordination, laboratory, and medical and pharmaceutical supplies. Patient care statistics for this specific program mirror the Free Clinic's general statistics for adolescents. Half of patients seen in the adolescent clinic are females seeking contraceptive services or pregnancy testing. Another 26 percent of adolescents are seeking treatment of an STD. Various programs offered by the Free Clinic are utilized by adolescents. *Safe Space* is the Free Clinic's runaway shelter and is located next door. It provides services consistent with the regulations of the National Youth Runaway Act (Public Law 93-415) to almost 600 minors a year.[1] It is one of the very few runaway shelters in the country that is able to offer medical and legal services to its adolescent clients. Approximately 30 percent of adolescents seeking refuge at Safe Space request or are perceived to need medical care, which is available to them at the Free Clinic. Common reasons given by adolescents for needing medical care include documentation of physical abuse and reproductive health concerns. Safe Space retains its own attorney on salary in order to represent its adolescent clients to the judicial system. The attorney handles approximately 30 to 40 cases each month.

Other Free Clinic services used by adolescents include ambulatory medical care and general counseling and outpatient drug abuse treatment services. The Free Clinic sponsors the *Adolescent Sexual Offender Project* and an *Incest Survivors' Group*. For general issues, master's prepared mental health professionals include adolescents as part of their individual caseloads. The Adolescent Sexual Offender Project, which started in 1986, is largely funded through a contract with the county's Juvenile Court. It has a capacity of 20 clients and includes family members in its treatment services. The Free Clinic's dental service is very small and provides emergency care for less than 100 patients a year. Very few adolescents use this service.

Staff—The Free Clinic's staff includes 42 paid employees and more than 400 volunteers. In the medical services division, five paid coordinators provide supervision as well as direct patient care. The physician medical director provides direct patient care and supervises one to four family practice residents per month. Licensed medical volunteers at the practitioner level include 30 physicians, 22 dentists, 6 nurse practitioners, and 6 physician assistants. In addition, 80 to 90 medical students volunteer at the Free Clinic each year.

The mental health staff consists of four part-time counselors for the Adolescent Sexual Offenders' Project and 4.5 full-time master's prepared counselors to provide general mental health and substance abuse treatment services. Approximately 50 volunteer therapists also maintain active caseloads of clients.

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[1] See ch. 14, "Homelessness: Prevention and Services," in Vol. II, for a discussion of Federal laws pertaining to homeless and runaway adolescents.

Continued on next page

Box 15-B—The Free Medical Clinic of Greater Cleveland—Continued

Legal services are staffed by 15 volunteer attorneys, who provide advice and referral by telephone.

Budget and Funding—The Free Clinic's annual budget, including operation of its runaway shelter, is $1.2 million. The funding mix is 60 percent public and 40 percent private moneys.

The largest proportions of public moneys are from the Ohio State Department of Health for STD control and HIV testing and from the County Drug Board. Federal funds for family planning services made available under from Title X of the U.S. Public Health Service Act help to support the Free Clinic's family planning program.[2] The Free Clinic does not bill Medicaid or private insurance companies for patients who may be eligible for these benefits.

Private resources come from foundations, corporations, individual contributions, and other sources. The privately funded portion of the budget is generally less restricted than the portion from categorical government grants and contracts. One observer has noted that it is highly unusual for integrated health services programs to have such a high proportion of unrestricted funds available and that such unrestricted support is important to the long-term viability of integrated programs (128a). Foundation grants have remained quite stable since the Free Clinic's inception and support its general operating costs. This arrangement is quite unusual, given that foundations frequently prefer to support demonstration projects. Corporate contributions are assuming an increasingly important role in the overall budget, as the Free Clinic's Board of Trustees becomes more active in fundraising. Although individual contributions made up 37 percent of the 1990 budget's private resources, such contributions are regarded as the budget's least stable section. The Free Clinic's annual individual fundraising campaign goal is partially determined by its anticipated budget deficit; the funds generated through individual fundraising are used to offset these expenses. In addition the Free Clinic's staff sponsor at least one special fundraising event each year (e.g., rock concert) that raises approximately $25,000. The Free Clinic also operates a Thrift Store, which breaks even financially each year.

Volunteers are important to the Free Clinic. The Free Clinic's overall monetary budget is enhanced by 80 percent, and its personnel budget is doubled, by the almost $1 million of service time that its volunteers contribute. Personnel costs absorb approximately 75 percent of the Free Clinic's operating budget. Seventeen percent of nonpersonnel costs pay for medical supplies, laboratory fees, and other general operating costs.

The budgetary goals of the Free Clinic are to develop a diverse funding base, so as to allow services to continue despite possible interruption of individual funding sources, and to enhance the proportion of funding from stable corporate contributions. The Free Clinic considers itself fortunate to have had a relatively stable external funding base over the past decade, through continuation of its multiple grants and contracts.

Strengths—The Free Medical Clinic of Greater Cleveland has been able to grow over the 2 decades of its existence for several reasons. It has enjoyed consistent, strong leadership. There have only been three directors during this time period. It has been recognized as an important community resource, as witnessed by its ability to attract and maintain a strong and varied public and private funding base. It has become a popular organization for volunteers, many of whom have continued their involvement with the Free Clinic for several years. It is located close to a university and its medical school, which allows many students to volunteer. It has retained its organizational identity and original mission.

Weaknesses—In some ways, the weaknesses of the Free Clinic represent the converse sides of its strengths. For example, the paid staff consist of only a few positions, each of which carries supervisory and direct service responsibilities. Staff turnover can be especially troublesome. The Free Clinic may find it difficult to recruit certain paid staff positions because salary levels are significantly below those of other local health care institutions. Consequently, individuals who are attracted to working at the Free Clinic are frequently young adults with a strong altruistic commitment and a sense of social advocacy.

Conclusion—There has been no formal evaluation of the ability of the Free Clinic to meet the needs of adolescents and others in the community. The current director of the Free Clinic has stated that it serves as a "bandaid," a short-term and incomplete solution to the community's problem of providing financial access to health and medical care for all its citizens, including individuals who perceive themselves as alienated from mainstream society and who are not willing to seek care from its traditional sources.

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[2] Title X of the Public Health Service Act is discussed in ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

SOURCE: M. Hiller, Executive Director, The Free Medical Clinic of Greater Cleveland, information provided in an interview conducted for OTA by Trina Anglin, M.D., Ph.D, Director of Adolescent Medicine, Cleveland Metropolitan Hospital, Cleveland, OH, Apr. 16, 1990.

service center known as "The Door" is frequently described as the prototype of an integrated, comprehensive service model for adolescents. This section describes its programs in detail.

The Door is an independent, community-based facility in New York City that offers comprehensive health and medical care, mental health and drug treatment, educational, legal, social services, recreational, creative arts, and employment training services for youth up to age 21. It opened in 1972, following more than a year of planning and development activities by a multidisciplinary group of professionals who were concerned about the physical health, mental health, and social issues of youth living in New York City. The Door's initial quarters were donated as free space, and for its first 7 months of operation, its staff were unpaid volunteers. Originally, the Door was begun as a model substance abuse prevention program (101). However, the Door was adopted as a model project by the International Center for Integrative Studies to demonstrate an integrated human services approach to the well-being of adolescents. The center seeks to promote interdisciplinary communication and cooperation among the humanities, and the behavioral, social, and life sciences (280).

The Door is currently located in a renovated building in lower Manhattan. It serves approximately 7,000 adolescents annually and reports approximately 70,000 visits a year (101,128). About 75 percent of the adolescents who use the Door for their physical health and mental health care do not have health insurance coverage, either public or private. An estimated 22 percent of adolescents who use the Door are covered by Medicaid, and an estimated 3 percent have private third-party insurance coverage (101). No more than 7 percent of the Door's operating budget is recovered from Medicaid; although a sliding-scale payment system is operational, out-of-pocket payments by the Door's clients are negligible (128). The Door's annual budget is supported by more than 80 funding sources, including Federal, State, and local public agencies, as well as private foundations, corporations, and individuals.

The Door's staff consists of approximately 70 full-time-equivalent paid positions and more than 75 volunteers. The staff is divided into three interdisciplinary working teams, which meet regularly to review the needs and progress of their adolescent clients. Staff members include physicians, nurse practitioners, nurses, family planning counselors, health educators, nutritionists, pharmacists, laboratory technicians, medical assistants, psychiatrists, psychologists, social workers, lawyers, teachers, vocational rehabilitation counselors, job developers, youth workers, and physical education instructors and artists from the creative, visual, performing, and martial arts (101). These staff members provide a wide spectrum of services for the adolescent clients of the Door. Important to the Door's philosophy is its combination of case management and interdisciplinary teamwork. Following a comprehensive in-depth assessment, each adolescent client is assigned to a primary counselor, who will coordinate care and assure continuity and quality of care throughout the client's involvement with the Door. The primary counselor works closely with the interdisciplinary therapeutic team built around each client with acute or broad-ranging problems.

The Door's Adolescent Health Center offers general medical services; a prenatal, young parents, and child health program for the young children of adolescent parents, including on-site nursery services; a health care program that offers ongoing continuity of care to youth who have no regular source of health care or who have chronic diseases such as asthma, diabetes and hypertension; family planning and sex counseling services; and a nutrition counseling service. The approximately 3,500 adolescents enrolled in the Adolescent Health Center make about 18,000 total visits per year.

The Door's Psychiatric Services provide diagnostic assessment and therapy using a number of treatment modalities, including crisis intervention, individual and group psychotherapy, individual and group drug and alcohol counseling, pharmacotherapy, couples and family counseling, milieu therapy, and art and recreational therapy. Many of the adolescents seen in the Door's Psychiatric Services have problems related to the use of substances. The Door's Drug and Alcohol Education Services provide information and education about substance use and treatment resources. In addition to helping adolescents on-site, the Door has an active outreach program for students enrolled in schools, and for adolescents who congregate on the streets and in parks.

The Door's Social Service Program provides social crisis intervention and supportive counseling for adolescents with emergency needs for shelter, food, and clothing, including adolescents who have run away. Social services staff help young people to develop more constructive communication and working relationships with their families. They facilitate mobilizing other agencies' resources for their youthful clients.

The Door supports three separate counseling services which help adolescents to address educational, vocational, and legal issues. The Educational Counseling Services Program offers educational evaluation and diagnosis, counseling for adolescents who are truant from or who have quit school, tutoring, remediation for youth with learning disabilities, and help with the admissions process to college. The Learning Center Program provides both ongoing assistance to adolescents having difficulties at school and an alternative education program for students who have quit school. The Door's Vocational Counseling Services provide work readiness evaluation, vocational testing, career counseling, vocational training, job shadowing, and job placement. The Legal Counseling Services Program offers legal advice, representation on civil and criminal cases, and assistance in dealing with public agencies and in receiving public benefits. The program helps to divert appropriate clients from the justice system to the Door's Mental Health Counseling Services. It also advocates for legal reform concerning minors.

The Door's Creative and Performing Arts Workshops Program allows adolescents to try a wide range of possible career choices and creative expressions, to learn to work cooperatively, to learn work-related skills, and to develop pride in their skills. The creative workshops are perceived as valuable vocational and life training experiences and include a variety of classes in dance, theater, music, fine arts, crafts, photography, silkscreen, sculpture, pottery, jewelrymaking, and plastic arts. The Door's Recreation and Physical Education Program, which includes classes, games, and team formation in a variety of activities such as gymnastics, martial arts, wrestling, weight lifting, aerobics, and ball sports, emphasizes working cooperatively with peers and gaining a respect for good health. The Door also sponsors recreational and educational field trips as part of its overall program of constructive adolescent-oriented activities.

The Door's Food Services Program prepares a free, nutritious evening meal for adolescents, many of whom otherwise would not receive adequate nourishment. This program also helps adolescents to learn how to plan and prepare nutritious meals, with particular attention to hygiene and the use of institutional equipment.

Other programs at the Door focus on long-term issues. For example, the Mental Health, Drug and Alcohol Treatment Program provides long-term treatment for adolescents with serious problems in these areas. The program uses a combined case management and interdisciplinary team approach to plan, implement, and monitor individualized treatment, using the Door's many resources. Adolescents become involved with a therapeutic milieu but continue to live outside the Door.

The Door has grown from a small program staffed primarily by volunteers into a large, complex organization. However, it has retained the elements that define the service characteristics of an integrated community health delivery program. It offers comprehensive services at a single site. It interacts with other community agencies through referral networks and tracks youngsters who are referred to another agency for care. It performs multiproblem needs assessments for individual adolescent clients. The Door's service model is based on the concept of an interdisciplinary team that meets regularly to coordinate the efforts of its individual providers. Finally, the Door is committed to case management, so that each adolescent client has a single, primary contact person to coordinate programmatic elements. As part of this model, a single, unified record is maintained for each adolescent (34).

Staff members are flexible in their roles and serve as advocates for their clients. Through the case management approach, the Door has continued to make it easy for its adolescent clients to use its facilities. In addition, its afternoon and evening hours of operation were established for the convenience of its clients, so that adolescents who attend school do not need to miss classes to participate in the Door's programs.

Even though the Door is frequently cited as the model health program for adolescents, it should be understood that it probably cannot be replicated exactly in the majority of communities in the United States. But its underlying principles of care can clearly be adopted by other communities. As discussed by Jellinek (127), the Door had certain advantages during its formative period. First, its parent organization, the International Center for Integrative Studies, provided extremely high caliber technical expertise, which has allowed the Door to develop its unique management structure and professional staff mix in the context of its organizational goals. Second, its placement in New York City has given the Door access to a large and diverse pool of professional talent, and consequently, the ability to be selective in its choice of staff members. The Door's location in New York City gives it another advantage relative to other communities. Because New York has a superior public transportation system linking all boroughs, and because adolescents in New York usually learn to navigate it independently at an early age, access to the Door's single, stationary site is not a problem. In contrast, public transportation systems in the majority of other cities are not as well-developed or convenient to use as New York's is, so that a single location of services may not be as accessible.

School-Linked Health Centers

The SLHC model for providing comprehensive health services to adolescents has received considerable attention and has the potential to reach many medically underserved adolescents because of its capacity to be replicated in many communities. The first SLHC opened in West Dallas, Texas, in 1970 and offered a variety of services previously unavailable in a school setting, focusing principally on general primary care. In 1973, the first SLHC to emphasize reproductive health services (along with primary health care services) was established at the St. Paul High School Clinic in Minnesota (142). Box 15-C describes a typical SLHC in Birmingham, Alabama.

The number of SLHCs in this country has grown dramatically in recent years, particularly in the latter half of the 1980s.[46] Unfortunately, it is impossible to develop a good estimate of the number of adolescents who have access to an SLHC for several reasons. First, there is no national, comprehensive source of information on the number of operating SLHCs. This situation stems in part from the dynamic nature of the school-linked health care movement. Also, there are varying definitions of what constitutes an SLHC. OTA uses the term SLHC to refer to any school health center for students (and sometimes the family members of students and school dropouts) that provides a wide range of medical and counseling services and is located on or near school grounds and is associated with the school. But some researchers confine their work to centers based on school grounds and others consider a school with an on-site, part-time nurse practitioner, to have an SLHC. A number of States have recently undertaken initiatives in school-linked health care, some with programs that go far beyond traditional, primary health care (e.g., New Jersey includes job training and employment services in its program).

Photo credit: © Randall Hagadom, Titusville, NJ

There is as yet little systematic evidence that school-linked or community-based comprehensive service centers for adolescents improve health outcomes, but there is clear evidence that such centers can improve adolescents' access to the health and related services that are most likely to be needed by adolescents.

Almost all the data on SLHCs that are available are collected and disseminated by two groups: the Center for Population Options' (CPO) Support Center for School-Based Clinics and the Robert Wood Johnson Foundation's School-Based Adolescent Health Care Program. Both programs are actively engaged in supporting and promoting the SLHC model of health care for adolescents. Data from other sources is extremely limited.

CPO, which surveys SLHCs annually, limits its research to SLHCs operating on school grounds (i.e.,

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[46] At least 39 new clinics opened during 1987 alone, when many communities received funding from the Robert Wood Johnson Foundation's national School-Based Adolescent Health Care Program.

Box 15-C—The Ensley High School "Extra Help Services Clinic": A School-Linked Health Center in Birmingham, Alabama

The Ensley High School school-linked health center—named in a vote by students as the "Extra Help Services Clinic"—in Birmingham, Alabama, was established in 1987. The Jefferson County Department of Health established the center with financial support from the Robert Wood Johnson Foundation's School-Based Adolescent Health Care Program.

A community advisory committee, composed of local clergy, legislators, school officials, parents, adolescents, and health officials, played a significant role in the health center's planning and development and continues to monitor the health center's performance. With input from discussions at several public forums and a planning survey of the school's faculty, students, and their parents, the advisory committee determined the scope of the center's services. The planning survey found that one out of three Ensley High School students had not seen a doctor in 2 or more years and that treatment for minor injuries and illness was most frequently requested by parents, closely followed by athletic and employment physicals, alcohol and drug abuse counseling, and treatment for sexually transmitted diseases. Although the county health department has final responsibility for the health center, the advisory committee also approves any changes in its procedures and services.

The Ensley High School health center provides physical exams; acute care; care for chronic conditions, such as diabetes and high blood pressure; immunizations; dental, vision, and hearing screening; lab tests; nutrition counseling, including an exercise and weight management program; reproductive health care, including pap smears, birth control education and referral, and treatment for sexually transmitted diseases; prenatal care and parenting education; individual, group, and family therapy; and vouchers for prescription drugs for those students who cannot afford them.

The Jefferson County Department of Health provides a number of services not available at the school health center, including contraception, specialized lab tests, surgery, and long-term mental health counseling. Although these services are provided off-site, the health center staff continue to manage cases referred outside the center and follow up students to ensure that all of them get the services to which they are referred.

In the 1988-89 school year, more than 70 percent of Ensley High School's students were enrolled to receive the school health center's services with their parents' permission. Of the visits to the health center that year, 45 percent were for acute illness, 15 percent for psychosocial services, 9 percent for physical exams, 9 percent for reproductive health care, 4 percent for prenatal care, 3 percent for chronic conditions, and 2 percent for sexually transmitted disease treatment. More than half of the patient visits to the center last over 20 minutes. Supporters of the clinic emphasize that the compassionate care and personal attention provided by health center staff go beyond the services represented by the statistics. School faculty support has been especially important to the center's success; faculty account for approximately 45 percent of referrals to the health center.

The Ensley High School health center is open Monday through Friday, 7:30 a.m. to 4:30 p.m., and is staffed by a full-time family nurse practitioner, registered nurse, and receptionist. A pediatrician, social worker, nutritionist, and mental health counselor are part-time staff.

SOURCE: Jefferson County Department of Health, "Witness to the Possible: Ensley High School Health Center," Birmingham, AL, no date.

school-based clinics)[47] and appears to omit a number of the State programs (e.g., New Jersey and New York). In 1990, CPO reported that, in the 1988-89 school year, it surveyed 153 on-site SLHCs in 96 communities in 32 States (117).[48] Ninety-five schools responded. Most of the SLHCs surveyed by CPO served senior high school students and are located in low-income neighborhoods of large cities.[49] CPO's data suggest that a *minimum* of 233,600 U.S. adolescents, less than 1 percent of the country's 31 million adolescents overall, have access to an on-site SLHC.[50] Although this estimate falls short of

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[47] CPO plans to broaden the scope of its survey to include off-site SLHCs in its future research; however, data from on-site and off-site SLHCs will be analyzed separately (296).

[48] There are 35,786 middle, junior high, and senior high schools nationwide; the overwhelming majority of schools do *not* have an SLHC.

[49] In 1988, only 15 of the 120 existing on-site SLHCs were in junior high or middle schools.

[50] This number was calculated by multiplying the number of on-site SLHCs surveyed by CPO in 1988-89 (i.e., 153 times average enrollment of schools with surveyed SLHCs in 1988-89 (i.e., 1,527) (153 × 1,527 = 233,631).

Box 15-D—Adolescents' Perspectives on Their Need for a School-Linked Health Center

One way of assessing the *need* for school-linked health centers (SLHCs) is to ask adolescents whether they need and will use the services if implemented. Although many programs have conducted needs assessments as part of planning activities for the development of SLHCs, few programs have published their findings. One health needs assessment, which was conducted in a Rhode Island public high school in preparation for the opening of a school health clinic, found that the majority of students expressed a willingness to use the specified clinical services. In addition, students who acknowledged problems or behavior in defined areas, including depression, history of suicidal intention or attempt, obesity, and sexual activity (but not substance use), were significantly more interested in using relevant clinical services than students who did not report such concerns or behaviors (227).

The State of New Jersey Department of Human Services surveyed approximately 3,600 high school students to determine their knowledge about and frequency of use of established helping resources (237a). It found that although the majority of students could identify helping resources for problems with school, work, their families, health, sexually transmitted infections, finding a job, and depression, there were significant gaps between knowing about helping resources and actually using them. The largest gaps were for help with health services and personal problems. This survey also found that students were most likely to identify the school as a helping resource, regardless of the type of problem. In addition, the large majority of students who had actually sought help from the school were satisfied with the help they had received. Based on these findings, the State Department of Human Services recommended that New Jersey's School-Based Youth Services Program should provide both health information and staff to help students with personal problems (237a).

A study of SLHCs in New York City public schools found that 38 percent of interviewed students reported that they would not have sought help for a problem addressed by the SLHC if no clinic had existed (304).

SOURCE: Office of Technology Assessment, 1991.

the actual number, it is obvious that the overwhelming majority of U.S. adolescents do not have access to an SLHC.

Services Provided by SLHCs[51]—Data on the services provided by the on-site SLHCs surveyed by CPO are presented below. Although all SLHCs aim to provide a wide range of health care services, what they offer varies and depends largely on clinic resources, the particular needs of the community's adolescents, and local attitudes towards providing reproductive health services in a school-linked setting. Several surveys that have asked adolescents about their needs for a school health center are summarized in box 15-D.

Medical Services—In 1988-89, 90 percent or more of the on-site SLHCs surveyed by CPO provided general primary health care, assessment and referrals to community health care services, diagnosis and treatment of minor injuries, diagnosis and treatment of sexually transmitted diseases, general as well as sports and employment physical examinations, laboratory and pregnancy tests, prescriptions for medication, and referrals for prenatal care (see table 15-9). A slightly smaller proportion (80 to 89 percent) of SLHCs also provided assessment/referral to private physicians, chronic illness management, gynecological examinations, and immunizations. Services at junior high/middle schools and senior high schools are generally similar, although it appears that junior high/middle schools are less likely to provide referrals to community health care or private physicians.

Counseling/Educational Services—Common counseling/educational services include health and nutrition education, sexuality counseling, pregnancy counseling, mental health and psychosocial counseling, and weight reduction programs. Most SLHCs responding to the CPO survey provided all those services considered to be counseling or education (see table 15-10). The services least likely to be delivered were job counseling, parenting education, and drug/alcohol counseling. Less than half the

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[51] Data presented here on the services provided by SLHCs are drawn from a 1988-89 survey of on-site SLHCs conducted by the Center for Population Options (CPO) (117). Ninety-five of the 153 on-site SLHCs known by CPO to be operating during the 1988-89 school year participated—a 62-percent response rate. The respondents represented 27 of the 32 States in which SLHCs were located and 56 of the 96 communities. Participating schools included senior high schools, junior high/middle schools, vocational schools, and schools going from kindergarten through grade 12 (117). The definitions of the service categories (i.e., medical, counseling/education, and family planning) are CPO's.

Table 15-9—Percentages of On-Site School-Linked Health Centers Which Offer Medical Services, by Type of School, 1988-89[a]

Medical service	Type of school Senior high (n = 76)	 Junior high/middle (n = 11)	All schools (N = 95)
Diagnosis/treatment of minor injuries	99%	100%	98%
General primary health care	97	100	97
Laboratory tests	97	100	97
Physical exams for sports/work	97	100	97
General physicals	96	100	96
Pregnancy tests	93	91	93
Prescribe medication	92	100	92
Referral for prenatal care	91	100	91
Assessment/referral to community health care	93	55	90
Diagnosis/treatment of sexually transmitted diseases	92	82	90
Gynecological exams	90	91	88
Chronic illness management	87	100	87
Immunizations	90	100	87
Assessment/referral to private physician	90	55	85
Dispense medication	72	82	74
EPSDT screening[b]	49	55	48
Pediatric care for infants of adolescents	38	18	38
Prenatal care (on-site)	38	18	36
Dental services	28	55	31

[a] Data presented in this table are drawn from a 1990 survey conducted by the Center for Population Options (CPO). Ninety-five of the 153 on-site SLHCs (i.e., school-*based* clinics) known by CPO to be operating during the 1988-89 school year participated—a 62-percent response rate. The respondents represented 27 of the 32 States in which SLHCs were located and 56 of the 96 communities. Participating schools included senior high schools, junior high/middle schools, vocational schools, and schools going from kindergarten through grade 12.

[b] EPSDT is Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program.

SOURCE: H.J. Hyche-Williams and C. Waszak, "School-Based Clinics: Update 1990" (Washington, DC: Center for Population Options, 1990).

Table 15-10—Percentages of On-Site School-Linked Health Centers Which Offer Counseling and Educational Services, by Type of School, 1988-89[a]

Counseling/educational service	Type of school Senior high (n = 76)	 Junior high/middle (n = 11)	All schools (N = 95)
Health education	100%	100%	100%
Nutrition education	100	100	99
Sexuality counseling	97	91	96
Pregnancy counseling	92	91	91
Mental health and psychosocial counseling	91	82	91
Weight reduction programs	91	82	90
Sex education in classroom setting	87	73	85
Family counseling with students and parents	83	73	82
Drug and substance abuse programs	63	73	66
Parenting education	65	46	62
Job counseling	32	9	30

[a] Data presented in this table are drawn from a 1990 survey conducted by the Center for Population Options (CPO). Ninety-five of the 153 on-site SLHCs (i.e., school-*based* clinics) known by CPO to be operating during the 1988-89 school year participated—a 62-percent response rate. The respondents represented 27 of the 32 States in which SLHCs were located and 56 of the 96 communities. Participating schools included senior high schools, junior high/middle schools, vocational schools, and schools going from kindergarten through grade 12.

SOURCE: H.J. Hyche-Williams and C. Waszak, "School-Based Clinics: Update 1990" (Washington, DC: Center for Population Options, 1990).

surveyed SLHCs provided a structured HIV prevention program in the classroom or on-site clinic (117).

Family Planning Services—Almost all on-site SLHCs surveyed by CPO provided counseling on birth control methods in 1988-89, although 3 of 11 responding junior high/middle schools did not (see table 15-11). Other common services include examinations, followup, and referrals for birth control methods. In 1988-89, 21 percent of surveyed SLHCs *dispensed* contraceptives, a decline from 28 percent in 1985-86. More than half (54 percent) of the surveyed SLHCs provided written prescriptions for birth control methods.

Table 15-11—Percentages of On-Site School-Linked Health Centers Which Offer Family Planning Services, by Type of School, 1988-89[a]

	Type of school		
Family planning service	Senior high (n = 76)	Junior high/middle (n = 11)	All schools (N = 95)
Counseling on birth control methods	97%	73%	94%
Followup for birth control methods	80	55	78
Referrals for birth control methods and exam	72	46	71
Examinations for birth control methods	72	55	70
Writing prescriptions for birth control methods	55	55	54
Dispensing birth control methods	20	27	21

[a] Data presented in this table are drawn from a 1990 survey conducted by the Center for Population Options (CPO). Ninety-five of the 153 on-site SLHCs (i.e., school-*based* clinics) known by CPO to be operating during the 1988-89 school year participated—a 62-percent response rate. The respondents represented 27 of the 32 States in which SLHCs were located and 56 of the 96 communities. Participating schools included senior high schools, junior high/middle schools, vocational schools, and schools going from kindergarten through grade 12.

SOURCE: H.J. Hyche-Williams and C. Waszak, "School-Based Clinics: Update 1990" (Washington, DC: Center for Population Options, 1990).

Sponsoring Agencies and Administrative Arrangements of SLHCs—The majority of SLHCs maintain organizational and administrative independence from their school system, although an increasing number are administered by community school districts (143). The designers of the first SLHCs intended that the centers remain fiscally and administratively independent of the schools that housed them in order to ensure patient confidentiality and encourage students' trust in clinic staff. In the 1985-86 school year, only 4 percent of the on-site SLHCs surveyed by CPO were sponsored by school districts; by 1988-89, 19 percent of them were administered by school districts (117,143). Some SLHCs report that school district sponsorship works well because it facilitates integration of school health services and eliminates a level of bureaucracy (55). According to CPO, SLHCs that are not sponsored by school districts are most commonly sponsored by public health departments (33 percent in 1988-89), community clinics (18 percent), and hospitals (18 percent) (117). Twelve percent of school-based SLHCs were sponsored by other entities. Many agencies operate more than one SLHC site.

In 1988-89, 91 percent of the SLHCs participating in the CPO survey were located inside a main school building serving an average enrollment of 1,527 students (with a range of 315 to 10,000) (117). More than half were open during the summer and almost one-quarter were open on holidays. Ninety percent were open either before or after regular school hours.

Staffing of SLHCs—SLHCs are usually staffed by nurse practitioners, physician assistants, and physicians to provide the majority of clinical care, and counselors or social workers to address mental health, substance use, and family issues (142,167). The training of physicians who staff SLHCs is more likely to be pediatrics than obstetrics and gynecology (184). Other specialized personnel include dental hygienists, nutritionists, dentists, and psychologists (184).

Most SLHCs try to employ staff with special expertise in adolescent health care. Although bilingual or bicultural staff may more effectively meet the needs of minority adolescents, and some funding agencies have made a special effort to hire them for SLHCs (28), as a general matter their numbers and availability are seriously limited (184).[52]

Eighty-two percent of the on-site SLHCs responding to CPO's survey employ a school nurse (117). In 44 percent of these schools, the school nurse is part of the clinic staff, performing such functions as delivering direct services, providing case management, participating in clinic staff meetings and case conferences, and serving on clinic advisory boards. In the majority of schools, however, the school nurse operates independently of the school clinic although she may refer students to the SLHC for further care (117).

Demographics and Utilization of SLHCs—It is well-documented that many adolescents in schools that have SLHCs use the centers and that a large proportion of adolescents in schools with an SLHC either have no other regular source of care or rely on a local emergency room for their medical care (156,168,184).[53] Nationwide, the average SLHC serves 59 students and has 183 visits per month, according to CPO (143). In 1987-88, almost half (48 percent) of the students who were eligible to use the services of on-site SLHCs surveyed by CPO enrolled to receive the center's services (143). Eighty percent of enrolled students used the centers' services at least once during the school year (143).

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[52] See ch. 18, "Issues in the Delivery of Services to Selected Groups of Adolescents," in this volume for a discussion of the special health care needs of minority adolescents.

Schools with SLHCs are typically located in low-income communities where access to health care is limited and lack of health insurance is common. Overall, approximately 55 percent of students enrolled in SLHCs surveyed by CPO had no other source of primary health care during 1988; in some programs this was true for almost 100 percent of clinic enrollees (168). Thirty-four percent of enrolled students were uninsured in 1988, more than twice the 15 percent national rate of adolescents without health insurance, according to CPO (150, 168).[54] Another indicator of the poverty of the communities in which the SLHCs surveyed by CPO are located is that 30 percent of enrolled students in 1988 had Medicaid coverage—three times the national average of adolescents with Medicaid coverage (150, 168). In 1988, only 36 percent of students enrolled in an SLHC had private health insurance (168).

The health needs of middle-class adolescents suggest the potential value of SLHCs in less impoverished areas (175,184). One study of middle-class adolescents residing in a suburban area found that almost half had unmet health needs that could be met by an SLHC or similar facility (175).

Although some schools with SLHCs serve predominantly white students, the large majority of students who currently use SLHCs are black or Hispanic (see table 15-12).[55] [56] Some SLHCs have been relatively successful in attracting male students; in 1988-89, 44 percent of SLHC patients in schools surveyed by CPO were male (117). One study found that SLHCs were more successful at attracting males than neighborhood or hospital-based clinics (84). Centers that offer and promote sports physicals are reported to be particularly successfully in attracting male students (184).

Table 15-12—Race and Ethnicity of Students Using On-Site School-Linked Health Centers, 1987-88[a]

Race and ethnicity	Percentage of school population enrolled in clinic (N = 130)
Black	59%
White	25%
Hispanic	12%
Other	4%

[a]Data presented in this table are drawn from a survey of on-site SLHCS (i.e., school-*based* clinics) conducted by the Center for Population Options (CPO).

SOURCE: D. Kirby, C. Waszak, and J. Ziegler, "Assessment of Six School-Based Clinics: Services, Impact, Potential" (Washington, DC: Center for Population Options, 1989).

Why Adolescents Use SLHCs—On average, 46 percent of visits to Robert Wood Johnson Foundation SLHCs lasted more than 20 minutes in the 1988-89 school year (156). The primary diagnoses of adolescents who visited 23 SLHCs sponsored by the Robert Wood Johnson Foundation in the 1988-89 and 1989-90 school years are detailed in table 15-13.[57] More than 80 percent of visits were for return patients. The leading primary diagnoses were acute illness or injury (26 percent), mental health problems (21 percent), and physical exams and other preventive services such as immunizations and vision and hearing testing (24 percent).[58] Reproductive health care accounted for 12 percent. Anecdotal reports from a variety of SLHC staff indicate a high prevalence of depression, sexual abuse, and parental drug use (184).

Mental health problems are often discovered in visits by adolescents visiting the health center for

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[53] An emergency room is the most costly site for acute care and is only appropriate for serious emergencies. Emergency rooms do not provide preventive medical care, health education, or ongoing support for emotional and psychological problems and other chronic conditions.

[54] See ch. 16, "Financial Access to Health Services," in this volume for further details on health insurance, Medicaid, and financial barriers to care.

[55] The Robert Wood Johnson Foundation found that racial and ethnic minority students accounted for more than three-quarters of the visits to the 23 SLHCs it supports (156).

[56] Most clinics serve only their student population, but some are also open to dropouts (16 percent), children of students (16 percent), other family members of students (11 percent), and adolescents in the broader community (143).

[57] In Vol. II, see ch. 5, "Accidental Injuries: Prevention and Services," for a description of adolescents' accidental injuries, ch. 6, "Chronic Physical Illnesses: Prevention and Services," for a review of physical problems among adolescents, and ch. 11, "Mental Health Problems: Prevention and Services," for details on adolescent mental health problems.

[58] These diagnoses represent the principal reason for the visit and do not reflect other services that may have been provided.

Table 15-13—Principal Reason for Clinic Visits to 23 School-Linked Health Centers Funded by the Robert Wood Johnson Foundation, 1988-89 and 1989-90

	Percentage of visits	
Principal reason	1988-89[a]	1989-90[b]
Acute illness/accidents	25%	26%
Mental health related	20	21
Other, including immunizations, vision, and hearing testing	13	12
Reproductive health	13	12
Physical examinations	12	12
Chronic disease management	5	4
Acne, other dermatology	4	4
Nutrition, including eating disorders	3	3
Dental	<1	1
Drug and alcohol abuse	<1	1

[a]There were 49,377 total visits in the 1988-89 school year.
[b]There were 58,148 total visits in the 1989-90 school year.

SOURCE: J. Lear, Co-Director, School-Based Adolescent Health Care Program, Robert Wood Johnson Foundation, Washington, DC, unpublished data on student utilization of SLHCs, October 1990.

some other complaint (184). While drug and alcohol counseling are available at many SLHCs, the number of visits to the Robert Wood Johnson Foundation sites for substance abuse problems was negligible.

Financing Issues for SLHCs—Financing is a critical determinant of SLHCs' hours of operation, scope of services, and long-term viability. Current programs owe much of their existence to private foundation support. Recently, some State and local health departments, as well as school districts themselves, have begun to provide substantial financial support to local SLHCs. There is evidence that some programs have been able to receive Medicaid and private health insurance reimbursement for their eligible students, although the level of third-party revenues supporting SLHCs appears to be minimal.

Costs and Sources of Funding—The average operating budget for the on-site SLHCs surveyed by CPO was $143,827 in 1988-89 (117). In 1987-88, SLHC budgets ranged from $100,000 to $313,000, depending largely on clinic hours (143). It has been estimated that SLHCs cost between $50 and $150 per student per year (184). One study found that the average cost of a routine physical examination at a SLHC was considerably less than the cost of one performed in a private physician's office in the same community: $11.25 v. $45 (251). Considering the lost wages of parents who may accompany their children for the visit to a private physician increases the difference even further.

SLHCs are funded by a variety of public and private sources (e.g., see table 15-14). Most of the on-site SLHCs responding to CPO's survey are subsidized by at least two sources; more than half have three sources or more (143). In fact, program staff must often devote significant time to securing financial support, making fundraising itself a costly program activity (184). Foundation grants, although time-limited, have been key to the startup, development, and growth of SLHCs. Foundations typically provide seed moneys for startup with the expectation and intention that the successful project will garner more stable and long-term resources (87). As shown in table 15-14, 26 percent of the 1988-89 operating budgets of 79 SLHCs surveyed by CPO was derived from foundation grants; the percentage was lower than it had been in previous years, when foundation support accounted for as much as 41 percent of SLHC budgets (55,56). A significant percentage of foundation support for SLHCs comes from the Robert Wood Johnson Foundation's School-Based Adolescent Health Care Program, whose funding will end in 1993. It is not clear whether other moneys will be available to compensate. Continued changes in funding may create problems for SLHCs, because changes in grants sometimes necessitate changes in program content that are disruptive to program operations and confusing to students.

While the share of SLHC funding from foundations has been declining in recent years, the share of State funding of SLHCs has recently increased dramatically (see table 15-14). The increased share of State funding reflects a number of State initiatives supporting SLHCs (see box 15-E). In 1985-86, State health departments contributed 16 percent of funds for the operating budgets of SLHCs surveyed by CPO and city/county governments contributed virtually nothing; in 1988-89, State health departments contributed 28 percent of funds for surveyed SLHCs' operating budgets and city/county governments contributed 19 percent (55,117).[59] School systems often provide in-kind contributions of space, utili-

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[59] *Community health centers* provide health services to residents of low-income and rural communities or neighborhoods which have been designated medically underserved areas (87). The centers provide primary health services, including preventive, medical, dental, and mental health services. Public or private nonprofit organizations may receive grants to establish a community health center. A network of SLHCs has been established by a community health center in at least one State (87).

Table 15-14—Funding Sources for On-Site School-Linked Health Centers Responding to the Center for Population Options' Surveys, 1985-86 to 1988-89[a]

	Percentage of total operating budget			
Funding source	1985-86 (N = 61)	1986-87 (N = 45)	1987-88 (N = 92)	1988-89 (N = 79)
Public sources				
Maternal and child health block grants[b]	27%	14%	16%	11%[b]
EPSDT[c]	14	2	2	2
Other Medicaid	—	2	2	3
Title X[d]	3	NA	0.4	—
Title XX[e]	2	1	—	<1
School district	—	—	3	2
Community health center	2	NA	6	4
State health department	16	19	19	28
City/county	—	19	16	19
Other public	—	—	2	NA
Total public support	64%	57%	66.4%	70%
Private sources				
Foundation grants	31%	41%	31%	26%
Private health insurance	—	0.1	0.1	2
Patient fees	2	0.4	0.3	<1
Other private[f]	3	2	2	NA
Total private support	36%	43.5%	33.4%	29%
Total funding				
Estimated total funding (all centers)	NA	$9,200,000	NA	$11,362,000
Average operating budget	NA	$ 120,991	NA	$ 143,827
Range in operating budget	NA	$10,000 to $414,900	NA	NA

NA = Not available.

[a] Data presented in this table are drawn from surveys of on-site SLHCs (i.e., school-*based* clinics) conducted by the Center for Population Options (CPO).

[b] Maternal and child health block grants, authorized by Title V of the Social Security Act, are intended to reduce infant mortality, reduce the incidence of preventable disease and handicapping conditions among children, and increase the availability of prenatal, delivery and postpartum care to low-income mothers. In fiscal year 1988, the U.S. Department of Health and Human Services' Bureau of Maternal and Child Health distributed $444.3 million to States as maternal and child health block grants. Twenty-three centers received a portion of this funding in grants ranging from $8,260 to $135,727, and totaling more than $1.3 million. Similar data for earlier years are not available.

[c] EPSDT is Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program.

[d] Title X of the Public Health Service Act is a Federal program administered by the U.S. Department of Health and Human Services. It provides Federal funds for public or private nonprofit entities that offer family planning services. The fiscal year 1990 appropriation was $141 million.

[e] Title XX of the Public Health Service Act is a Federal program administered by the U.S. Department of Health and Human Services. It provides Federal funds for demonstration projects to encourage adolescents to postpone sexual activity and demonstration projects that provide comprehensive health and social services for pregnant or parenting adolescents. Annual authorizations were $9.5 million through 1992.

[f] This includes donations from private corporations and nonprofit organizations.

SOURCE: **1985-86 and 1987-88 data:** Center for Population Options, "SBCs: Update 1989," *Clinic News* 5 (4):7, Washington, DC, 1989.
1986-87 data: S. Lovick and R. Stern, "School-Based Clinics: 1988 Update" (Washington, DC: Center for Population Options, 1988).
1988-89 data: H. Hyche-Williams and C. Waszak, "School-Based Clinics: Update 1990" (Washington, DC: Center for Population Options, 1990).

ties, and maintenance, but they seldom have sufficient financial resources to provide substantial fiscal support. In 1988-89, local school districts provided 2 percent of the operating budgets of SLHCs surveyed by CPO (117).

As local funding and the number of SLHCs have increased, the relative share of Federal support has decreased (see table 15-14).[60] In the 1988-89 school year, 11 percent of SLHCs' operating budgets were supported by Federal maternal and child health block grants, a drop from 27 percent in 1985-86.[61] [62] The 1988-89 share of Federal support provided by Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, other Med-

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[60] Available data make it difficult to determine whether the overall level of Federal funding has changed. The majority of Federal dollars for SLHCs has come through maternal and child health block grants. Complete data on how these block grants are allocated is not available.

[61] Twenty-three of eighty-one SLHCs responding to a 1989 CPO survey reported receiving maternal and child health block grant funds that year: these ranged from $8,260 to $135,727 and totaled $1,338,419 (296).

[62] Federal maternal and child health block grants were consolidated under Title V of the Social Security Act in 1981 and can be used to provide services to a wider range of individuals than Medicaid because of more generous eligibility rules (87). Another advantage of maternal and child health grants is that SLHCs can use existing Title V personnel in public health departments as staff if the health department is willing to use the SLHC as one of its sites (87).

Box 15-E—State Initiatives in School-Linked Health Care

A number of States have implemented initiatives in comprehensive school-linked health care. Although privately funded school-linked health centers (SLHCs) have existed for some time, State efforts to authorize and appropriate funds for SLHCs are fairly recent. At least nine States, five of which are described below, have begun to establish programs or demonstration projects in school-linked health care.[1]

New Jersey

In 1987, the New Jersey State Department of Health Services provided 29 grants to public and nonprofit organizations to establish SLHCs in local communities as part of its School-Based Youth Services Program (SBYSP). Funding for New Jersey's SBYSP comes from a $6.5-million set-aside in the State budget. Grants of $250,000 are awarded to school districts that formulate plans for SLHCs. Participating communities must be willing to provide 25 percent of the cost incurred by the center either through direct funding or the use of community facilities (270). The SBYSP requires that the SLHCs offer certain core services, including job training and employment services, health screening and referrals, and mental health and family counseling services. Depending on the community's needs, some centers provide additional services, such as programs for adolescent dropouts, classes in parenting skills for adolescent parents, child care, transportation, nutrition counseling, and a 24-hour crisis hot line. The SBYSP emphasizes coordination among parents, communities, and schools in the provision of adolescent health-related services (270). In addition, the program encourages the involvement of students in assessing the needs of adolescents, in order to help identify and address the many problems facing adolescents (63).

Kentucky

Kentucky's initiative in SLHCs is modeled on New Jersey's approach of providing comprehensive services. Kentucky established a task force in 1990 to determine the specific guidelines for their $9.5-million program to fund 125 to 150 youth and family resource centers. State officials plan to implement the program in July 1991. Only school districts in which at least 20 percent of the student body is eligible for the Federal School Lunch Program can participate. Each eligible district will receive between $30,000 to $90,000 to establish a center and may subcontract with outside organizations (90).

Iowa

Iowa began a pilot demonstration in September 1990 that established four SLHCs, which are also modeled after New Jersey's SBYSP. Iowa's program, established by State legislation, is funded entirely by private foundations and is coordinated by the Child and Family Policy Center, a nonprofit organization. The State may consider legislation that authorizes funding for the SLHCs, after evaluating the current program (37).

Florida

In Florida, the State Department of Health and Rehabilitative Services and State Department of Education are jointly coordinating a program designed to supplement current school health services. Initial funding for the program is $2.9 million for fiscal year 1991 and $9.6 million per annum thereafter. Florida's program offers grants to local school districts and county public health organizations to develop programs based on one of the following four models: a *school health improvement project* which provides expanded health screening services and coordinates health services with parents and the community; *student support services teams* consisting of a psychologist, social worker, and nurse to provide mental health services, alcohol and drug abuse counseling, care for sexually transmitted diseases, and pregnancy consultation to serve the local elementary, middle, and high schools; *full-service schools* programs that will allow the State Department of Human Services to provide health, economic, and social services to both adolescents and parents on school grounds; and *locally designed programs* that are designed to meet the specific needs of a community (94).

New York

New York State's Department of Health, in cooperation with the State Departments of Education and Social Services, has conducted School Health Demonstration Programs since 1982 and currently funds 115 elementary, middle, and high school clinics (81). The program targets low-income and high-risk youth and provides primary care, preventive care, and health education for students and parents (304). The Departments of Education and Social Services also fund a Community Schools Project at 10 demonstration schools. These schools are required to be open at night, weekends, and during the summer, and offer a broad range of social, medical, recreational, and other human services (81).

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[1] The nine States are New Jersey, Kentucky, Iowa, Florida, New York, Connecticut, Illinois, Michigan, and Oregon.

SOURCE: Office of Technology Assessment, 1991.

icaid funds, Title X of the Public Health Service Act, and Title XX of the Public Health Service Act was 6 percent, a drop from 19 percent in 1985-86.[63] [64]

Medicaid and Private Health Insurance—To date, reimbursement from Medicaid or private health insurers has played a very limited role in the financing of SLHCs. In fact, five States (Arkansas, the District of Columbia, Florida, Utah, and Wisconsin) explicitly prohibit Medicaid reimbursement for physician services provided in school settings (178). At least one State (Colorado) has a Physician-On-Site Rule, which requires that a physician be on the premises at the time a service is provided for it to be eligible for Medicaid reimbursement (273). Such regulations preclude Medicaid coverage of most SLHC services because SLHCs typically rely on nonphysician providers (with part-time physician supervision) to minimize cost.

Half of the SLHCs surveyed by Palfrey et al. reported efforts to collect Medicaid payments in 1990 and one-third tried to collect private insurance (211). But CPO reported that Medicaid and private health insurance together covered only approximately 7 percent of the 1988-89 costs of SLHCs that it surveyed (117). There is no information available on how well Medicaid or private health insurance payments reimburse the actual cost of covered services (including the administrative costs related to billing).

The principal obstacles to collecting third-party revenues cited by SLHCs are that students do not know their family's insurance status, costs and paperwork are involved in billing Medicaid and private insurance, payment for services is sometimes refused by third parties, and providers are concerned about breaching confidentiality (87,211). Furthermore, many students in schools with health centers are not eligible for third-party coverage because they are uninsured (143,156,184).[65] Many low-income students with private health insurance coverage belong to HMOs, which by design usually refuse coverage for nonemergency services provided outside the health plan (211,273).

Many SLHC programs cite significant administrative obstacles in trying to become Medicaid providers (211). Palfrey's survey found that SLHCs operated by community agencies with billing expertise are the most likely to try to collect Medicaid and private insurance reimbursement (211). Several of the surveyed centers had a Medicaid eligibility worker on-site to facilitate eligibility (especially for pregnant students) (211). School-sponsored centers responding to Palfrey's survey did not bill Medicaid or private health insurance at all, perhaps because they lacked the necessary administrative systems and experience (211).

It is not clear how much incentive grant-supported SLHCs have had to pursue third-party financing; only half of centers surveyed by Palfrey (52 percent) even attempted to identify their students' Medicaid status in 1990 (211). The Denver school-based clinics studied the implications of billing third parties and found that it would cost more to bill for services than would be captured through available third-party sources (273). Some adolescents are particularly sensitive to questions asked about eligibility for health coverage and may turn away from available services rather than respond (101). And, there may be reason to question the wisdom of relying on third-party payment in a model of adolescent health care designed with several critical goals in mind: easy access, an atmosphere of trust and confidentiality, and low administrative overhead (101,211). Third-party billing could undermine these goals.[66] [67]

Parental and Community Attitudes Toward SLHCs—Nearly 90 percent of SLHCs responding to CPO's survey in 1990 required parental consent before students could use their services (117), although many surveyed clinics offered emergency services (57 percent), family planning (43 percent), and treatment for sexually transmitted diseases (47 percent) without parental consent if the law permits (117). Overall about half of parents gave permission for their adolescents to receive services from SLHCs responding to the CPO survey in 1987-88 (168); schools whose centers have been established for at least 1 year tend to have higher enrollment rates (56).

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[63] Title X of the Public Health Service Act was established by the Family Planning Services and Population Research Act of 1978. Title X provides Federal funds for public or private nonprofit entities that offer family planning services. The Title X program is administered by the U.S. Department of Health and Human Services. The Title X family planning clinics are required to serve adolescents (87). For further discussion, see ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

[64] Title XX of the Public Health Service Act was established by the Adolescent Family Life Act of 1981. Title XX provides Federal funds for demonstration projects to encourage adolescents to postpone sexual activity and demonstration projects to provide comprehensive services for pregnant and parenting adolescents. For further discussion, see ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

[65] See ch. 16, "Financial Access to Health Services," in this volume for further discussion of adolescents without Medicaid or private health insurance.

[66] For example, some State Medicaid programs send each Medicaid recipient family a monthly itemized list of the services that family members have received (87). Most private insurers send subscribers an explanation of benefits for every reimbursed service.

[67] See ch. 16, "Financial Access to Health Services," and ch. 17, "Consent and Confidentiality in Adolescent Health Care Decisionmaking," in this volume.

The issue that has engendered the most intense parental and community concern about SLHCs is how the centers manage issues of sexuality and reproductive health. A great deal of media attention has been directed towards SLHCs because of their family planning services (81). Considerable controversy has occurred in some communities during the planning and early implementation phases of SLHCs, and experience shows that successful SLHCs closely involve community representatives (184). Most SLHCs have advisory boards that include parents, members from local health departments, private sector physicians, church organizations, and youth service organizations (184).

Opposition to the establishment of local SLHCs usually focuses on pregnancy prevention activities and the fears that such activities will lead to increased sexual activity among students. The National Conference of Catholic Bishops, for example, is opposed to SLHCs that distribute contraception or provide abortion services on the grounds that such SLHCs are both: 1) "morally objectionable" because, in the view of the Bishops, they encourage premarital sex, and 2) "open to question even on practical [i.e., effectiveness] grounds" (193). However, the National Conference statement on SLHCs recognized that the basic health care needs of young people are not being adequately addressed and suggested that SLHCs "that clearly separate themselves from the agenda of contraceptive advocates may provide part of an effective response to the health needs of young people" (193).[68]

Concern that SLHCs have the effect of increasing sexual activity or abortions among adolescents is not borne out by existing research (131,143,194,316). More research has been conducted on the issue of whether the presence of SLHCs increases sexual activity rates among adolescents than on whether abortions are encouraged (e.g., 143,316).

Physician Attitudes Toward SLHCs—Organizations of health care professionals can have considerable impact on any attempts to modify existing health care delivery systems; thus, the attitudes of physicians and other health care professionals toward SLHCs may be important. OTA is aware of six published sources of information about health care professionals' attitudes toward SLHCs. These include a survey of pediatricians (8) and the positions of five physician groups (7,8,17,21,259).

Pediatricians appear divided in their attitudes towards SLHCs. In 1987, the American Academy of Pediatrics included questions about SLHCs in its national survey of a random sample of its membership and found that pediatricians' opinions were roughly equally divided between those supporting the concept, those who were neutral, and those expressing negative attitudes (8). Those holding negative opinions cited concerns over disruption of continuity of care, lack of cost-effectiveness relative to office-based care, duplication of existing services, and inappropriateness for adolescents with other sources of health care. Nonetheless, almost 60 percent of the surveyed pediatricians believed that SLHCs should dispense contraceptives to adolescents, and slightly more than half thought that parental consent should not be required for dispensing contraceptives. Overall, the survey found that pediatricians specializing in adolescent medicine and pediatricians who did not provide direct patient care held more positive attitudes towards SLHCs than did other pediatricians (8). What proportion of the pediatricians participating in the survey actually practiced in communities with an

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[68] A systematic effort that attempted to obtain informed citizen opinion on the issue of SLHCs was conducted by the Jefferson Center for New Democratic Processes at the request of the State of Minnesota Senate Health and Human Services Committee (126). The Jefferson Center convened eight groups at the local level, representatives of which went on to debate at the statewide level. All groups were presented with testimony from opponents and proponents of SLHCs. Of the eight local *groups*, one voted in opposition to clinics, three voted for alternatives, and four voted in favor. *Individuals* at the local level were more likely to be split on the issue of SLHCs, however, with 43 percent supporting clinics, 7 percent opposing, and 50 percent supporting alternatives. However, when citizens were selected to go to the statewide meeting, they were selected to be representative of opposing views. Thus, it is not surprising that citizens participating at the State level voted 13 to 11 to favor SLHCs at a modest level (i.e., in support of SLHCs that did not distribute contraceptives or provide abortion counseling), with 11 members opposing any introduction of SLHCs (126). However, this decision should be considered cautiously, because, from the outset, citizens were asked to consider the usefulness of SLHCs in preventing "teen pregnancy, AIDS, and other sexually transmitted diseases" (126), not as a means of providing basic health services to adolescents.

SLHC or had had personal experience with an SLHC is not clear.

Community physicians are commonly thought to oppose SLHCs because the clinics are viewed as competitors for patients (259). In fact, however, community physicians may not lose patient visits to SLHCs; there is some evidence that many adolescents are unwilling to visit their private physician for concerns about sexuality, substance abuse, or emotional upset and also would not be willing to seek care for these problems with their parents' knowledge (175). In addition, most SLHCs established to date have been located in medically underserved communities, and many of the adolescents who use SLHCs lack private health insurance or Medicaid coverage (143,156,184). Also, SLHC health screening may identify patients with health problems that require referral to a physician for more detailed assessment or continuing management (203). Most surveyed SLHCs refer students to community health care (90 percent) and to private physicians (85 percent) for further care (117). Findings from one evaluation of a school health demonstration project suggest that nurse practitioners working within SLHCs can establish successful referral relationships with community physicians (180,203).

Five physician groups have published positions relative to SLHCs: the American Academy of Family Physicians, the American Medical Association (AMA), The Society for Adolescent Medicine (SAM),the American Academy of Pediatrics (AAP), and the American College of Obstetricians and Gynecologists. In general, these positions can be characterized as partially supportive of SLHCs but more supportive of providing access to care through an individual office-based physician, who is seen as better able to provide continuous, comprehensive care.

The American Academy of Family Physicians "supports the *selective* implementation of school-based health clinic programs only in areas where the health care needs of the school age population are not being met" and urges that all clinics be staffed by family physicians (7). The academy also notes, however, that because of issues of confidentiality, consent, and compliance, adolescents may derive special benefits from access to care through school-based health clinics.

In 1987, the AMA adopted a resolution to study the efficacy of school-based health clinics, and its Council on Scientific Affairs later reported that school-based health programs "constitute a promising avenue for providing health services to adolescents, particularly in medically underserved areas" and "such programs hold sufficient promise to warrant careful evaluation" (22). Still, the association believes that ideally every child should have a "medical home" for continuing and comprehensive health care provided by a private physician, but recognizes that alternatives need to be explored when this is not possible.

In a statement similar to those of the American Academy of Family Physicians and the AMA, the AAP supported the selective implementation of SLHCs "in areas where the health care needs of the school-age population are not being met" (8). Much as the AMA did, the AAP preferred providing access to high quality health care services in a " 'medical home' where care could be provided in a continuous and comprehensive fashion" (8). In this respect, the AAP noted that there are "limits to the scope of services provided by [SLHCs]" and that "questions regarding the efficacy of [SLHCs] remain unresolved" (8).

The AAP also believes SLHC services should be supervised by a physician, but according to the AAP, pediatricians are preferred as supervisors of SLHC services. Interestingly, the AAP endorsed the extension of SLHC services to preadolescent children, because "the roots of adolescent health problems are found in increasingly younger school-aged children" (8).

The American College of Obstetricians and Gynecologists does not have a policy statement on SLHCs per se, but, in 1987, it endorsed the development of "programs, including those located in schools, to provide reproductive health services in areas where such services are not available to adolescents and where they have the support and input of parents and communities" (17).

SAM endorses SLHCs as a model of care with the potential to address the unmet health needs of adolescents and acknowledges the need for evaluation of the effectiveness of SLHC programs (259).

Evaluations of SLHCs—What is a successful outcome for a SLHC? Measuring success is not easy given the wide range of ambitious goals often hoped for by advocates of SLHCs, which include improving adolescents' access to a broad range of needed health care services; preventing pregnancy and sexually transmitted diseases among adolescents; reducing or eliminating substance abuse among adolescents; and reducing violence, chronic school absenteeism, academic failure, and school dropout among adolescents. In general, systematic evidence of the ability of SLHCs to improve *health outcomes* is not available, although this lack of information is not unique to SLHCs.[69]

Only two fairly rigorous evaluations of SLHCs have been conducted (143,316). The first was conducted to evaluate the impact on adolescent pregnancy of an SLHC in Baltimore, Maryland (316).[70] This evaluation, by Zabin et al., demonstrated a 30-percent drop in the pregnancy rate at the end of 3 years for sexually active adolescent females in the schools involved in the program; during the same time period, conceptions among adolescent females in the comparison schools increased 57 percent. Males and females at the schools that received classroom-based sex education and that were linked to the clinic demonstrated significant gains in sexual and contraceptive knowledge in comparison with a matched sample of students from similar urban Baltimore schools. Zabin et al. found that the SLHC was able to get participation among the male adolescents in the schools, particularly in informal group discussions and individual meetings with social workers who provided information on and distributed contraceptive devices (315). Another finding was that students exposed to the SLHC program increased their use of contraceptives and were more likely than students in comparison schools to visit the clinic for contraceptive counseling before initiating intercourse or in the first few months after initiating sexual activity. These results were strongest for those students who were exposed to the program for 2 years or more. The success of the program in terms of pregnancy prevention was attributed largely to the program's intensive focus on this goal. In addition, even though the SLHC was not on school grounds, it was nearby, and clinic staff worked with the schools, providing health education. The fact that the clinic was off-campus, and thus operated after school hours, was thought by some to be an advantage.

The second fairly rigorous evaluation of SLHCs is a CPO evaluation of six on-site SLHCs by Kirby, Waszak, and Ziegler (143). In comparison to early evaluations of SLHCs, which focused on the outcomes of delaying sexual activity and pregnancy, this evaluation compared a range of health outcomes for students in schools having SLHCs physically located in the schools with health outcomes for students in sociodemographically similar comparison schools in the same communities (four schools) or with baseline data (two schools). It is important to note that, for the most part, the Kirby et al. study assessed outcomes for the entire student body in both SLHC and non-SLHC schools, not just for clinic users. Although this approach was methodologically necessary in this case,[71] and fair in the sense that SLHCs are intended to affect the health of the entire student body, it does place a large burden on the SLHC schools in terms of demonstrating effectiveness. Other methodological approaches taken in this study that could have affected the outcome measures were basing almost all of the health outcome data on student self-reports, and using samples that, although quite large, were not sufficiently large to detect small changes or changes in infrequently occurring outcomes such as pregnancy.

In general, Kirby et al. found, the SLHC schools varied considerably in the extent to which they had an impact on sexual activity, contraceptive use, and the other risk-taking behaviors that were assessed (school absenteeism, alcohol consumption, and smoking) (143). On the positive side, students in the SLHC schools were not more likely to report being sexually active than their peers in the comparison schools. In two of the SLHC sites, students initiated sex at older ages (an average of 8 months later) than students in comparison schools; in the other SLHC sites, there were no differences between SLHC and non-SLHC schools; and in one community, data were not available to enable a comparison.

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[69] A long-term evaluation of the Robert Wood Johnson Foundation's School-Based Adolescent Health Care Program is currently underway and is designed to identify the health and health-related outcomes of the SLHCs supported by the foundation (230). In addition, DHHS' Centers for Disease Control (within PHS) is funding an evaluation of the ability of SLHCs to prevent adolescent pregnancy (290a).

[70] See ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II, for a more complete description of this evaluation.

[71] Comparisons between clinic users and nonusers in terms of clinic impact have the disadvantage of possible selection bias due to the different characteristics and motivations of students who choose to use the clinic and those who do not, and it was not possible to randomly assign students to use or not use the SLHC (143). It should also be noted that schools are not randomly chosen to have SLHCs or not. Comparison schools were chosen on the basis of physical closeness to the SLHC schools and relevant sociodemographic characteristics. Thus, although this evaluation was carefully done in a relative sense, it has some methodological flaws.

Students in two of the SLHC schools—schools in which the health center staff provided aggressive outreach for contraceptive education within the school—had higher rates of contraceptive use than students in the comparison groups did.[72] In three SLHC sites in which contraceptives were dispensed, however, students did not report higher rates of contraceptive use. According to Kirby et al., these findings suggest that the mere accessibility of contraception may not be sufficient to increase adolescents' contraceptive use. In the three SLHC schools in which clinic *users* were compared with nonusers, however, contraceptive use was higher among the clinic users, and, overall, from 44 to 90 percent of the pregnancies that occurred were to students who never had attended the clinic. None of the SLHC programs reviewed was able to demonstrate a significant impact on self-reported pregnancy rates[73] or birth rates[74] (143).

Kirby et al.'s findings with regard to other risk-taking behaviors similarly varied by school:

- Absenteeism—Relative to absenteeism due to illness in comparison schools in the same communities as the SLHC schools or baseline data, as relevant, there was less absenteeism due to illness in two SLHC schools, more absenteeism in one SLHC school, and no difference in absenteeism in three SLHC schools. There were no differences in number of days skipped (nonexcused absences) between any of the SLHC schools and the comparison schools.
- Cigarette Smoking—Relative to cigarette smoking in comparison schools in the same communities as the SLHC schools or baseline data, as relevant, there was less frequent smoking at one SLHC site (where students at the SLHC school underwent a psychosocial assessment at their first clinic visit designed to identify students who engaged in risk-taking behaviors and might therefore need counseling) and no difference in the frequency of smoking at the three other SLHC sites where cigarette smoking was measured as an indicator of effectiveness.
- Alcohol Consumption—Relative to alcohol consumption in comparison schools in the same communities as the SLHC schools or baseline data, as relevant, there was significantly lower alcohol consumption at three of four SLHC sites where alcohol consumption was measured; differences were primarily in the "never or rarely consumed" categories.
- Illegal Drug Use—Relative to illegal drug use in comparison schools in the same communities as the SLHC schools or baseline data, as relevant, there were no differences in illegal drug use at the two SLHC sites where questions about illegal drug use were asked.[75]

Kirby et al. also attempted to measure the impact of SLHCs on students' utilization of medical care (143). Only the SLHC that employed a full-time physician and arranged for all students to receive an examination when they first entered the school had an impact on the likelihood of students' having seen a doctor recently: 72 percent of students in the SLHC school, but only 61 percent of the students in the comparison school, had seen a doctor within the previous 12 months. The percentage of students who had received a physical examination, a blood test, and a urine test within the last 2 years, or who had seen a dentist recently, also was higher in the SLHC school than in the comparison school. According to Kirby et al., these findings suggest that "clinics that have a large staff, offer a wide array of services, and make a concerted effort to bring students into the clinic would have greater impact on students' receipt of health care than clinics that do not meet these conditions" (143). There were no differences in any SLHC schools in students' receipt of care in hospitals or emergency facilities.

Many of the adolescents who use SLHC services are those who have no other source of care, and adolescents who use the centers typically use them for typical urgent care for illness and injuries and for services otherwise unavailable without high levels of income, generous insurance policies, or breaches of confidentiality (e.g., mental health counseling, reproductive health care) (117,143,156).

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[72] Some of the changes attributed to one school's program may have resulted from the intensive education about acquired immunodeficiency syndrome (AIDS) that was occurring concurrently (143).

[73] These data were at the school level, not just for clinic users compared with nonusers.

[74] Birth rates were measured in two sites only.

[75] Kirby et al. suggest that it may not be valid to measure illegal drug use through self-reports (143).

Quality of Care in SLHCs—OTA is not aware of any study examining the quality of care provided in SLHC settings. It is not yet known how well patients are followed or if centers are appropriately linked to community health care providers (184).

One indication of quality of care is patient satisfaction (275). Although little is known systematically about students' satisfaction with SLHCs, anecdotal evidence suggests that adolescents who use the services are often very satisfied with them. In addition, Kirby et al.'s evaluation of six on-site SLHCs found that adolescents used and were satisfied with the services for many of the reasons such services have been provided on or near school grounds. Kirby et al. found that the three reasons for using the SLHC most often cited were: 1) the clinic was part of the school and users felt they could trust it, 2) the clinic was easy to get to, and 3) the staff was caring (143). Students who cited one of these reasons used the SLHC more frequently and for a greater variety of services than students who did not cite these reasons (143). Kirby et al. found that the longer students had been in a school, the more likely they were to have used the SLHC (143). Most (43 to 87 percent) of the students who did not use the SLHC cited lack of need. Some of these students (8 to 21 percent) said they did not feel comfortable at the clinic, and others (0 to 12 percent) were concerned about confidentiality. In general, however, little is known about the differences between adolescents who use SLHCs and those who do not, and obtaining such information is key to understanding how well SLHCs serve adolescents in need (184).

Limitations of SLHCs—The SLHC model for the delivery of care to adolescents has several important limitations. Some communities are resistant to any model of care that confronts the issue of adolescent sexuality (154). Despite evidence that there have been no increases in adolescents' sexual activity or pregnancy rates after the opening of an SLHC, community and parents' concerns that SLHCs will encourage adolescents to engage in sexual activity have been able to halt or delay the introduction and funding of programs on both the local and Federal level.[76] Shortages of adequately trained providers, especially bilingual/bicultural nurse practitioners and mental health professionals, are also a significant obstacle to the large-scale implementation of SLHC programs (154).

Even with mandatory school attendance laws, many U.S. adolescents—especially those at high risk for bad health outcomes—drop out of school by the 10th grade (154). Nationwide, 27 percent of American students drop out of school before high school graduation; twice as many drop out from schools located in poor, urban areas.[77] Thus, if SLHC programs were widely implemented but limited to adolescents attending school, many adolescents would not be reached.

Another limitation of SLHCs is that most SLHCs operate only during or around school hours, thus precluding access to care on weekends, holidays, and summer vacations. Although it could be improved, however, this feature does not make SLHCs much different from many private, office-based physicians' practices.

Finally, it should be noted that not all SLHCs are able to establish reliable referral ties to community hospitals and other local health care providers (154).

Following their multiyear, in-depth evaluation of six SLHCs in cities throughout the Nation, Kirby et al. identified several specific limitations of SLHCs and suggested that SLHCs could take a number of steps to enhance their effectiveness in preventing pregnancies and reducing students' risk-taking behavior in other areas (143):[78]

- Finding that SLHCs "generally do a good job of treating and counseling students who seek their services, but they rarely have aggressive programs to identify risk-taking teens who are not motivated to come to the [SLHC]," Kirby et al. suggested that SLHCs *identify and target students engaged in risk-taking behaviors*. To improve the identification and targeting of such students, SLHCs could schedule routine physical examinations for all incoming students, administer psychosocial assessments, and urge teachers and other personnel to refer risk-taking adolescents to them.

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[76] The White House has acknowledged that school clinics could reduce adolescent pregnancy rates and the number of single-parent families but was reported to have rejected a proposal by an interagency group to fund school clinics because the proposal would be seen as "promoting promiscuity" and "may cause political problems among groups that are opposed to birth control" (214).

[77] See ch. 4, "Schools and Discretionary Time," in Vol. II.

[78] Kirby et al. noted that some SLHCs had already implemented the suggested recommendations. Thus, not all deficiencies are characteristic of all SLHCs.

- Finding that "most students use SLHCs infrequently," Kirby et al. suggested that SLHCs *conduct more outreach in the schools* (e.g., by participating in a comprehensive sexuality education program, placing posters about the center and health-related topics throughout the school, writing a regular column in the school newspaper, and making presentations at school assemblies).
- In another recommendation aimed at increasing students' access to health services and information, Kirby et al. recommended that SLHCs *offer group sessions facilitated by trained clinic staff to provide students with more opportunities to resolve difficult personal dilemmas* about sex and other risk-taking behaviors. At the same time, such sessions would help students become familiar with clinic staff.
- Finding that "students were far more likely to use a [SLHC] for reproductive health care if the clinic prescribed or dispensed contraceptives as well as offered counseling about birth control methods and pregnancy testing," Kirby et al. suggested that SLHCs *provide comprehensive reproductive health services.*
- Finding that "teens are impulsive and may not be willing to wait a week or longer to make important decisions about sex," Kirby et al. suggested that *appointments for family planning counseling and for birth control should be offered promptly, ideally on a walk-in basis, and that clinics follow up family planning patients more effectively* in order to improve contraceptive continuation rates.
- Finding that males have been much less likely than females to visit a school-based clinic for contraceptives, but that it is possible to increase the use of condoms by males, Kirby et al. suggested that *reproductive health programs should place greater emphasis on male responsibility and attempt to reach males through sports physicals, classroom activities, and the media.*
- Finding that many adolescents were not highly motivated to delay pregnancy, Kirby et al. suggested that SLHCs initiate measures to *provide greater motivation for delaying pregnancy.*[79]
- Finding that SLHCs "cannot effectively address any difficult social problem in isolation," Kirby et al. suggested that SLHCs *develop communitywide programs that involve parents, youth-serving agencies, religious and other community leaders, and the media.*
- Finding that many adolescents are already sexually active by the time they enter high school, Kirby et al. suggested that *SLHC services and health education be delivered earlier (e.g., in middle and junior high schools).*
- Finding that some of the cost-saving measures engaged in by SLHCs lead to heavy staff turnover, reducing the continuity of the relationships that can be developed between the clinic and students,[80] Kirby et al. suggest that SLHCs *increase permanent staff.* In order to implement the strategies proposed by Kirby et al., many SLHCs would also need to *hire additional staff.*

Adelman and Taylor came to somewhat similar conclusions about the limitations and unmet opportunities for SLHCs in their review of the provision of mental health services in SLHCs (5). Adelman and Taylor are the recipients of a Robert Wood Johnson Foundation grant to develop, implement, and evaluate models and networking resources for the mental health component of SLHCs (5), and they have developed a guidebook (271), newsletter (e.g., 272), clearinghouse, and other activities using the grant.

Adelman and Taylor found that mental health services, although the most frequently requested services in many schools and SLHCs, are not comprehensive and underserve students; existing programs tend to follow the traditional model of serving only those who seek care (5). The integration of mental health services into the daily life of school has been difficult, and SLHC mental health staff have often tended to operate in relative isolation from other school programs. In Adelman's and Taylor's view, better integration is necessary for the development of new and potentially more effective models for mental health intervention, such as group counseling and other means of early intervention. Adelman and Taylor see the development and testing of such models as a research opportunity for the mental health field.

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[79] For example, Kirby et al. suggested that pregnancy prevention messages be presented within the context of a life planning curriculum, where students are encouraged to extend their education and begin a career before beginning a family, and that role models and job opportunities in the community be provided (143). Pregnancy prevention strategies are discussed more fully in ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

[80] For example, "to save money, some clinics use rotating physicians from nearby medical schools," others "pay low wages and lose full-time staff once they have gained sufficient experience to command higher salaries elsewhere," and others "reassign more experienced staff to several schools or community health clinics in order to take wider advantage of their skills" (143).

In conclusion, SLHCs are a relatively new and potentially promising way of reaching adolescents in need of health services. There are still ways in which existing SLHCs can be improved upon; improvements will continue to require fresh and creative approaches to the delivery of health care and the integration of clinical services with health promotion and education, systematic evaluation of these approaches, and resources to both implement and evaluate the SLHC approach.

Other Innovations in the Delivery of Health Services to Adolescents

Integrated Health Services

The previous discussion focused on various types of comprehensive health centers for adolescents, including adolescent health care clinics associated with hospitals, multiservice centers such as the Door, and SLHCs located in or near schools. Although providing comprehensive services to adolescents at a single site ("one-stop shopping") may be preferred (34), it is sometimes not feasible. In such cases, community health delivery programs can strive to be integrated.

According to an interdisciplinary study group convened at the 1986 conference on Health Futures of Adolescents, integrated programs for adolescents could provide comprehensive services at a single site and offer extensive community referral, networking, tracking and followup services; conduct multiproblem needs assessments of adolescents seeking services as well as for the larger target population of adolescents; coordinate the services of interdisciplinary teams of health professionals; ensure unrestricted eligibility for services; have a single, primary contact person to coordinate services; and rely on a single, unified record for each adolescent (34).

Numerous administrative, clinical, and programmatic factors interfere with the delivery of integrated services to adolescents, however (34,182) (see box 15-F). Recommendations to promote and maintain integrated community health delivery for adolescents have included the following:

- collecting and disseminating of an expanded information on both National and State levels regarding demographic and morbidity profiles of adolescents;
- supporting systems designed to promote the integration of comprehensive interdisciplinary services for adolescents;
- training service providers to facilitate their assimilation into interdisciplinary health teams;
- evaluating the effectiveness of integrated models to promote implementation of optimally designed systems to meet adolescent health needs;
- widely disseminating evaluation research;
- supporting funding philosophies and policies consistent with the goal of integration of services;
- supporting the development and continuation of integrated health delivery models that, at a minimum, include: general medical, family planning, mental health, and social services;
- exploring methods of expanding traditional health services to include the following (either directly or through community linkages): legal assistance, vocational guidance; learning disabilities assessment; nutrition counseling; prenatal care; drug abuse assessment and counseling; recreational opportunities (34,307).

Similar recommendations were recently made by the Education and Human Services Consortium, although those recommendations were not limited to services for adolescents, and they addressed relationships among agencies, as well as relationships among providers within agencies (182). According to the consortium, five elements are key to high quality comprehensive service delivery: 1) the availability of a wide array of prevention, treatment, and support services; 2) techniques to ensure that children and families actually receive the services they need (e.g., co-location of staff from one organization to "branch offices" located at other agencies whose clients they share; "one-stop shopping," and an approach to case management that makes it a problemsolving partnership among

Box 15-F—Obstacles in the Development and Maintenance of Integrated Community Health Delivery Programs as Identified by the Study Group on Integrated Community Health Delivery Programs of the 1986 Conference on Health Futures of Adolescents

Obstacles identified by the Study Group on Integrated Community Health Delivery Programs for Youth of the 1986 Conference on Health Futures of Adolescents included: 1) problems encountered by administrators in promoting and developing programs; 2) clinical and programmatic barriers faced within organizations in the delivery of integrated services; and 3) issues specifically related to adolescents served by these programs. The specific issues identified by the Study Group are noted below:

Administrative Issues

- *Lack of comprehensive adolescent health databases at both national and community levels.* The ability to identify service needs of adolescents rests on the availability of comprehensive databases that reflect the entire range of health problems of youth.
- *Nature, level, and sources of funding for adolescent health programs.* Funding is categorical (i.e., agencies earmark funding for specific, rather than comprehensive, services) and low. Interests and philosophies conflict among funding agencies, providers, and parents.
- *Inertia among policymakers toward adolescent-related interests, stemming from lack of public awareness regarding adolescents' problems and the impact of those problems on the health, social, and economic well-being of communities.* In addition, integrated community health delivery programs for adolescents are an "essentially money-losing venture, one that is both labor intensive and nonrevenue producing."

Clinical and Programmatic Issues

- *Lack of models on which to base new delivery systems and adapt existing organizations of services.* Feasibility research has been positive, but impact evaluation studies have been limited in number and funding, and generally have not been conducted by outside evaluators. In addition, comparative studies of program outcomes are lacking.
- *Health care providers have not been trained to work in interdisciplinary community health delivery settings, and often experience conflict and ambiguity as to leadership and programmatic responsibilities.*
- *Providers lack awareness and skills in considering and incorporating services of a broad range of health and related community programs outside the single site setting, and often fail to include these resources as part of the intervention plans for clients.*
- *Providers and adolescents may differ from each other socially and culturally.*

Youth Issues

- *Consumers of integrated services are adolescents, who are "among the most powerless and disenfranchised citizens" in the United States.*
- *Attitudes towards youth are negative.*
- *The number of adolescents in the population is declining, at the same time that there is an increasing recognition of health problems of the elderly.*
- *Adolescents have not been acculturated to be active consumers of health services.* Maximum utilization of health services in an integrated setting requires that the recipient be an active consumer of health services. In addition, they should not expect that health services alone will cure one's problems.

SOURCE: L.H. Bearinger and E.R. McAnarney, "Integrated Community Health Delivery Programs for Youth: Study Group Report," *Journal of Adolescent Health Care* 9:36S-40S, 1988.

practitioners and clients); 3) a focus on the whole family; 4) giving children and families a voice in identifying and planing how best to meet their own needs; 5) measurement of the effectiveness of interventions in terms of outcomes for clients (182). Further, the Consortium suggested that both *service delivery and systems levels*[81] go beyond initial stages of *cooperation* to true *collaboration* in order to connect children and families with comprehensive services.[82] [83]

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[81] According to the consortium, at the *service delivery level*, interagency initiatives focus on meeting the needs of individual children and families. At the *system level*, initiatives are focused on creating a set of policies and practices that can help to build a communitywide network of comprehensive service delivery (182).

Efforts To Involve Adolescents in Health Services Planning and Management

A third innovation in the delivery of health services to adolescents involves encouraging adolescents' participation in policysetting and service delivery. This approach has recently been used by health providers in some mainstream institutions. Two health maintenance organizations, for example, are involved in efforts to make their programs more responsive to adolescents' needs by routinely seeking the advice and working participation of adolescents (134,159).

As part of this adolescent health assessment, OTA established a youth advisory panel to provide OTA staff with an adolescent perspective on the issues in the report. The youth advisory panel consisted of 21 individuals who ranged in age from 10 to 19. Panel members represented a range of backgrounds: racial/ethnic (white, non-Hispanic; Hispanic; Asian; black), socioeconomic, and experiential (e.g., homeless, substance use, pregnant, parenting, children of divorce, children from stepfamilies and extended families). Although all were from the greater Washington, DC, metropolitan area, they came from central city, suburban, and rural areas. During its meetings, the youth advisory panel highlighted important health issues for adolescents, developed a list of desirable features of health services and made recommendations to the project staff on ways to improve adolescent health. Representatives of the youth advisory panel also attended various workshops and meetings held by OTA. In one of the panels' meetings, members were asked to "role play" groups of service providers, program administrators, and health planners. Box 15-G summarizes each group's recommendations regarding key components of health care services for adolescents.

Photo credit: Kaiser Teen and Young Adult Health Center, Granada Hills, CA

Adolescent participation can take the form of special adolescent advisory panels or adolescent representatives on general advisory boards. The Kaiser Permanente HMO in Granada Hills, California, asks adolescents to provide advice on a regular basis.

Conclusions and Policy Implications

Conclusions

Adolescents' Need for Health Services

This Report makes it clear that adolescents do have need for health services. The health-related conditions of adolescents that cry out for prevention and treatment intervention include, but are not limited to:[84]

- fatal injuries, from accidents,[85] suicide,[86] and homicide[87];

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[82] According to the consortium, "In a *cooperative arrangement* at the service delivery level, partners help each other meet their respective organizational goals. . .without making any substantial changes in the basic services they provide or in the rules and regulations that govern their agencies." At the system level, "*cooperative initiatives* assess the need for more comprehensive services and recommend strategies to coordinate existing services." At the service delivery level, "*collaborative partnerships* establish common goals. . ., agree to pool resources, jointly plan, implement, and evaluate new services and procedures, and delegate individual responsibility for the outcomes of their joint efforts." *Collaborative ventures at the system level* are empowered. . .to negotiate, as well as to advocate for, programs and policies leading to more comprehensive service delivery" (182).

[83] The consortium's report provides examples of human services agencies that have been successful in structuring partnerships.

[84] Adolescent health problems are also discussed in detail in Vol. II: *Background and the Effectiveness of Selected Prevention and Treatment Services*, and summarized in app. B to this volume, "Burden of Health Problems Among U.S. Adolescents."

[85] See ch. 5, "Accidental Injuries: Prevention and Services," in Vol. II.

[86] See ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II.

[87] See ch. 13, "Delinquency: Prevention and Services," in Vol. II.

Box 15-G—Summary of Recommendations by the Youth Advisory Panel for OTA's Adolescent Health Project

An unusual feature of OTA's adolescent health assessment was that it included a youth advisory panel to provide OTA staff with an adolescent perspective on issues in the report. At one of the group's meetings, youth advisory panel members were asked to "role play" groups of service providers, program administrators, and health planners. The recommendations of each group with respect to key components of health care services for adolescents are presented below.

Recommendations of "Service Providers"

1. Clinics should be free.
2. Adolescents need many services, including dental care, dermatology, counseling, and gynecology services. Health care providers should not assume that all adolescents seeking services are pregnant.
3. Services should not be different by racial/ethnic group. However, services must be sensitive to geographic and cultural needs.
4. Services should remain open during evening hours for emergencies and on weekends.
5. Services should be centrally located and offered under one roof (comprehensive services), and the number of sites should be determined by population size.
6. Shuttle bus service should be provided.
7. There should be separate clinics for adolescents. Adolescents should be able to bring their *own* children to the clinic, but their parents should not be able to attend the clinic unless the adolescent asks him/her to come.
8. Services should be provided at school in school-based clinics or near the school.
9. Sex education in the schools should be made mandatory.
10. Hot line charges should not appear on phone bills (e.g., hot line calls should be 1-800 numbers).

Recommendations of "Program Administrators"

1. Money to run the services should come from the Federal Government and should be specific to adolescents.
2. Funds from services that are already targeting adolescents should be pooled into one adolescent fund.
3. The Federal Government must develop a payment/insurance plan for services where adolescents can pay a particular amount to receive all services (almost like a health maintenance organization). This system must be voluntary.
4. Eligibility for services should be based on some socioeconomic criteria.
5. Special attention should be paid to low-income adolescents and those not in school.
6. Adolescents should be informed about available services through word of mouth, television, radio, recreation centers, posters, and flyers in the mail.
7. Services should be based on developmental needs and not necessarily on age (e.g., not all 10-year-old adolescents need the same services).
8. Adolescents under age 21 should be able to receive services but should not be automatically cut off at that age.
9. The system should be flexible.

Recommendations of "Health Planners"

1. Adolescents should be included as full voting members on adolescent youth service agency boards.
2. There should continue to be a youth advisory group advising Congress on adolescent issues.
3. Youth awareness about particular health problems should be increased.
4. Adolescents should be involved in outreach activities (e.g., counseling adolescents who have been raped or have thought about suicide).
5. Youth should be encouraged to volunteer. Although adolescents do not necessarily have to be paid for their work, they need to know why they are doing what they are doing.

SOURCE: Office of Technology Assessment, 1991.

- **family problems**, such as maltreatment, which is higher among adolescents than among younger children[88];
- **school problems**, such as the potential for dropping out[89];
- **appropriate use of discretionary (nonschool) time**[90];
- **physical problems**, such as acute respiratory illnesses, which are the leading cause of school-loss days[91]; serious chronic physical illness and disability, experienced by perhaps 5 percent of adolescents (see ch. 6[92]); or sports injuries, which account for at least 1.04 million emergency room visits in a year (1988 data)[93]);
- **new problems experienced on reaching puberty**, such as dysmenorrhea and acne[94];
- **nutritional concerns**, such as overweight or obesity[95];
- **dental problems**, such as dental malocclusion, experienced by perhaps 13 to 16 percent of 12- to 17-year-olds (1970 data)[96];
- **problems associated with involvement in unprotected sexual activity**, such as sexually transmitted diseases; including HIV infection, which is as high as 3.7 percent among homeless and runaway adolescents at a shelter in New York[97]; and pregnancy, experienced by 1 million female adolescents a year[98]);
- **mental health and behavioral problems**, such as subjective distress, experienced by perhaps 25 to 40 percent of adolescents; diagnosable mental disorders, experienced by 18 to 22 percent of adolescents; suicide attempts, made by 15 percent of 10th graders[99]; heavy drinking,[100] reported by 11.1 percent of high school seniors; daily cigarette smoking, reported by 7.7 percent of high school seniors; daily marijuana use, reported by 2.9 percent of high school seniors[101]; commission of an illegal (delinquent) offense, reported by the majority of adolescents (1976 data)[102];
- **homelessness and associated health problems**, estimated to be experienced by 1 million adolescents; and[103]
- **further, some adolescent behavioral problems are interrelated** (81,209a), itself suggesting the need for an integrative approach to service delivery.

The Adequacy of the Mainstream Health Care System for Adolescents

It is not clear that American adolescents' needs for health services are, or can be, met entirely by the traditional U.S. mode of health service delivery—i.e., care provided on a routine or as-needed basis by private office-based physicians. Some of the health problems experienced by adolescents are conditions experienced by individuals of other ages (e.g., respiratory disease, chronic disabilities), and one might expect that adolescents with these conditions would seek care from physicians in the mainstream health services system. Other problems, though not unique to adolescents, may be new for them (e.g., gynecological and skin problems). For some problems, adolescents may not seek care from the mainstream health services system. Some issues may be considered ''normal'' for adolescents (e.g., acne, dysmenorrhea, subjective distress, delinquent behavior), and adolescents may not be advised that the problems are amenable to health services intervention. Finally, some problems may not be amenable to resolution through the health care system, but may require other types of human services (e.g., legal assistance, job training, tutoring, recreational opportunities).

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[88] See ch. 3, ''Parents' and Families' Influence on Adolescent Health,'' in Vol. II.

[89] See ch. 4, ''Schools and Discretionary Time,'' in Vol. II.

[90] See ch. 4, ''Schools and Discretionary Time,'' in Vol. II.

[91] See ch. 6, ''Chronic Physical Illnesses: Prevention and Services,'' in Vol. II.

[92] ''Chronic Physical Illnesses: Prevention and Services,'' in Vol. II.

[93] See ch. 5, ''Accidental Injuries: Prevention and Services,'' in Vol. II.

[94] See ch. 6, ''Chronic Physical Illnesses: Prevention and Services,'' in Vol. II.

[95] See ch. 7, ''Nutrition and Fitness Problems: Prevention and Services,'' in Vol. II.

[96] See ch. 8, ''Dental and Oral Health Problems: Prevention and Services,'' in Vol. II.

[97] See ch. 9, ''AIDS and Other Sexually Transmitted Diseases: Prevention and Services,'' in Vol. II.

[98] See ch. 10, ''Pregnancy and Parenting: Prevention and Services,'' in Vol. II.

[99] See ch. 11, ''Mental Health Problems: Prevention and Services,'' in Vol. II.

[100] Heavy drinking is defined as having had five or more drinks ''in a row'' in the 2-week period prior to the survey.

[101] See ch. 12, ''Alcohol, Tobacco, and Drug Abuse: Prevention and Services.''

[102] See ch. 13, ''Delinquency: Prevention and Services,'' in Vol. II.

[103] See ch. 14, ''Homelessness: Prevention and Services,'' in Vol. II.

This chapter has addressed selected major issues in the role of the *mainstream primary health care system* in meeting the health care needs of U.S. adolescents.[104] Historically, the provision of health care has been viewed primarily as the province of physicians (80,119). Thus, care provided by private office-based physicians has been the focus of much of the research on health care providers' ability to meet the health care needs of adolescents (e.g., 286,287). Primary care has not been defined to everyone's satisfaction, but some definitions suggest that the primary care physician should be able to provide the "medical home" for continuing and comprehensive health care that adolescents, and individuals in all age groups, need (21,263). OTA found that U.S. adolescents are relatively unlikely to use the services of private office-based primary care physicians, having the lowest rate of use of any age group. Although 73 percent of U.S. adolescents reportedly had one or more physician contacts in 1988, adolescents had the lowest rate of visits per person per year (1.6 visits per person per year to private office-based physicians on average; lower for nonwhite adolescents). Adolescents are also among the least likely to be hospitalized.

Among the possible reasons why adolescents with health concerns may not seek the services of physicians for health care is that, with the exception of specialists in adolescent medicine—who are few in number—there is no group of physicians who are clearly defined as appropriate to provide care to adolescents. The American Academy of Pediatrics has suggested that pediatricians be the primary health care providers for individuals up to age 21. A 1980-81 survey of pediatricians found, however, that only 40 percent of pediatricians continued adolescent care to the age of 18, and 42 percent refused to accept a new patient who had reached the age of 16 (226).[105] Thus, it is not surprising that only about one-quarter (23 percent) of adolescents' visits to private office-based physicians in 1985 were to pediatricians, and two-fifths were to general and family practice physicians (35 percent) or internists (5 percent).[106] However, other physicians are also unlikely to report much interest in providing health care to adolescents.

Despite the fact that only about one-quarter of adolescents' visits to office-based physicians are to pediatricians, much of the research on aspects of physician behavior with adolescent patients has been conducted with respect to pediatricians. Research suggests that pediatricians spend an average of approximately 1 minute more with adolescents than they do with other noninfant patients, for an average of 11 minutes per visit.[107] The duration of visit is potentially important because it is believed that many adolescent health problems may be preventable if adolescents are provided with "anticipatory guidance" from health care providers. As can be inferred from the listing of problems above, adolescents are at high risk of mortality and morbidity caused by social, and perhaps preventable, factors. However, the only study that assessed the amount of time spent by physicians (pediatricians) providing anticipatory guidance found that office-based general pediatricians spent an average of 7 seconds per visit on anticipatory guidance for adolescent patients ages 13 to 18 (223). This study and others have varied in their findings concerning what physicians discuss with their adolescent patients, with a more rigorous (e.g., direct observational) study and surveys of adolescents themselves finding that little time is spent discussing the "new morbidities" issues or the health concerns of importance to adolescents themselves.

Another important area of physician behavior that may affect adolescents' seeking of health care from private physicians is patient confidentiality. Again, findings reported in the present chapter, limited though they are, are variable, with 75 percent of members of The Society for Adolescent Medicine and a random sample of pediatricians expressing support for confidentiality for adolescent patients, but a survey using a specific example (a pregnant 15-year-old's desire that her mother not be told of the pregnancy) finding that the majority of physicians would not abide by the patient's request for confidentiality.[108] Some adolescents with ready access to a private physician expressed their unwillingness to seek a private physician's care for concerns about certain issues (sexuality, substance abuse, emotional upset) or to seek care for those problems with their parents' knowledge (175).

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[104] The chapters that discussed the prevalence and incidence of problems among adolescents also discussed the capability of problem-specific health and related care systems to meet the needs of adolescents who do experience these problems (e.g., STD diagnosis and treatment clinics, the mental health system, the substance abuse treatment system, the juvenile justice system), and found that, although information about utilization and access is scarce and difficult to come by, gaps appear to exist in almost all services.

[105] It may be important to note that this survey was published in 1983, and that more recent information on pediatricians' practices is not available.

[106] As discussed in ch. 6, "Chronic Physical Illnesses: Prevention and Services," in Vol. II, leading reasons for visits to private office-based physicians were for respiratory system diseases (17 percent), injuries (16 percent), and skin conditions (10 percent).

[107] The average visit time across all physicians was between 6 and 10 minutes (see figure 15-3).

A third important issue in health care providers' behavior examined by OTA is competence in diagnosing and treating adolescents' specific problems. Research on this issue, too, is limited. Among other concerns (e.g., lack of methodological rigor), a very small body of empirical work has explored this issue, most studies in this area have focused on the identification of mental health and substance abuse problems, and most of the work has involved the practices of pediatricians. The evidence that is available, however, suggests the following:

- Primary care physicians appear to have difficulty in identifying children who have behavioral and emotional problems.
- Physicians as a group are currently not able to identify substance abuse problems very effectively.
- Primary care physicians appear able to identify acne in adolescent patients, but their ability to treat acne has not been tested.
- Hospital services do not appear to adequately document health problems in adolescent patients.
- Physicians, nurses, social workers, psychologists, and nutritionists all consider themselves relatively untrained in important areas of adolescent health (e.g., sexuality, handicaps, endocrine problems, contraception, psychosocial concerns).[109]

The important issue of health care providers' ability to interact with adolescents—regardless of the specific problem that an adolescent may have—has received very little investigation.[110] [111]

Perhaps more disturbing than findings that many health care providers are apparently not able to treat adolescents, several studies have found that health care providers have expressed relatively little interest in additional training. Although there are no systematic national counts of the number of U.S. health care providers who have been specially trained to deal specifically with adolescents, approximately 1,400 nonpsychiatrist physicians (most of whom are pediatricians) identify themselves as adolescent medicine specialists, 1,400 psychologists express a special interest in adolescents, and there are 1,500 members of the American Society for Adolescent Psychiatry. There are no counts of other health care providers specializing in the treatment of adolescents. A structured experience in adolescent health became a required aspect of training for future pediatricians in January 1990, although no patient age range nor duration of training was specified. Neither family practice nor internal medicine include specific curricula regarding adolescents. Thus, those adolescents who seek health care are likely to see providers who have not been specially trained to work with them.

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[108] The laws, ethical statements of health care provider organizations, and consequences of not respecting confidentiality, are discussed more fully in ch. 17, "Consent and Confidentiality in Adolescent Health Care Decisionmaking," in this volume.

[109] Issues related to the role of emergency personnel who come in contact with adolescents (e.g., those who have been in accidents, been assaulted, or attempted suicide) are discussed in ch. 5, "Accidental Injuries: Prevention and Services," in Vol. II.

[110] It is important to note that even the limited amount of research on the attitudes and behavior of health care providers suggests that there is considerable variability among providers. With respect to some aspects of health care provider behavior and perceived competence—the provision of anticipatory guidance, maintaining confidentiality—younger physicians, and physicians who have more adolescent clients, have been found to be more likely to behave in ways that are compatible with adolescents' stated needs for health care delivery. In the case of the 15-year-old who wished to keep her pregnancy from her mother, the majority of obstetrician-gynecologists were likely to maintain confidentiality. With respect to the self-perceived competence of health care providers, there are substantial differences by physician specialty and profession. Physicians specializing in adolescent medicine—few as they are—are more likely to support confidentiality of care for adolescents, and have been found to evoke more satisfaction from adolescent clients. In the one study that involved nonphysician health care providers, nurses, social workers, and psychologists expressed more interest in additional training than did physicians.

[111] Financial issues may be a quite important factor in the ability of any particular adolescent to gain access to health care services. Lack of coverage may affect physicians' willingness to see adolescents, and the willingness of health care and other organizations to implement new services (see below). Both the problem of having no health insurance—which affects one out of seven adolescents—and the problem of having inadequate benefits for services or settings of importance to adolescents—which affects many of the other six out of seven adolescents—are discussed in ch. 16, "Financial Access to Health Services," in this volume.

Federal support for interdisciplinary training in adolescent health care is lower than it was in fiscal year 1981. In fiscal year 1990, the Federal Government was supporting only six such programs, at an average level of $300,000 annually (212). The small number of such programs, the limited funding for them, and program goals emphasizing research and leadership development over actual health service delivery have meant that few frontline health care providers have received interdisciplinary training in adolescent health care. Except for this interdisciplinary training program, Federal support for training specifically in adolescent health care for providers—across all disciplines—who are likely to care for adolescents and for those health care professionals who currently provide health and related services to adolescents is nonexistent.

Innovations in the Delivery of Health and Related Services to Adolescents

Given the apparent failure of both the primary health care system and the specialty health care systems to meet the health care needs of all U.S. adolescents, several innovations in health care delivery have been attempted. These include the provision of comprehensive health services at a single site (e.g., hospital-based adolescent health care clinics, community-based adolescent health care clinics, a teen center at an HMO, "free clinics," multiservice centers, and, most extensively, SLHCs), attempts to integrate services, and efforts to involve adolescents in health services planning and management.

Attempts to provide a range of health and related services to adolescents in a single setting using providers from multiple disciplines—so-called comprehensive services—have generally been well received by parents and adolescents. To one degree or another, centers that provide comprehensive services for adolescents also make a special attempt to be responsive to common themes of adolescent health care, such as enhancing access through free care or use of sliding-fee scales, evening and weekend hours of operation, and guaranteed confidentiality of services. In addition, staff members who work in comprehensive health programs for adolescents choose to work there because they are committed to and enjoy helping adolescents. They often perceive themselves as advocates for adolescents, and work with adolescents to coordinate programs of care (230a,292). In school settings, coordination with school staff, and consequent attempts to influence school environments are important aspects of special adolescent health care centers (230a).

Systematic evidence of the effectiveness of comprehensive programs in terms of improving health *outcomes* is scarce, however. The only study to date that compared special hospital-based adolescent health clinics to hospital-based clinics without a special adolescent focus found no outcome differences after a year (84). However, the specially funded clinics were more successful in getting adolescents to disclose behavioral and lifestyle problems to their clinical providers, and consequently to obtain care for such problems (84). Reductions in school absenteeism, alcohol consumption, smoking, sexual activity, and pregnancy have been found in some schools with SLHCs, though not consistently.

What has frequently been found is that many of the adolescents who use the services of SLHCs are adolescents who have no other source of health care,[112] and that adolescents use SLHCs for typical urgent care for illness and injuries and for services otherwise unavailable without high levels of income, generous insurance policies, or breaches of confidentiality (e.g., mental health counseling, reproductive health care). Further, one of the few systematic studies of SLHCs suggests that efforts to meet the more intangible needs of adolescents have been successful: the primary reasons cited by students for using the SLHC in their school were that users felt they could trust it because it was part of the school; the SLHC was easy to get to; and the staff was caring (143). The number of repeat visits to some SLHCs is also cited as suggestive that SLHCs are responsive to the needs of adolescents as they perceive them (230a).

When it comes to adolescents, then, SLHCs and some community- and health-care-organization-based adolescent health care centers appear to respond to many of the shortcomings of the traditional health care system: They attempt to address the range of problems that many adolescents face (e.g., by providing care for acute physical illnesses;

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[112] This finding is confounded somewhat by the fact that most SLHCs have been purposefully situated in communities deemed to be medically underserved.

general medical examinations in preparation for involvement in athletics; mental health counseling; laboratory tests; reproductive health care; family counseling; prescriptions; educational services; vocational training; legal assistance; recreational opportunities; advocacy; coordination of care (e.g., with school personnel); advocacy[113]). Services are free or low-cost. Services are confidential. Staff are knowledgeable about adolescents. Staff are committed to helping adolescents in a way that is meaningful to the adolescents themselves. Settings are designed with adolescents in mind, to the extent possible. Adolescents are often involved in the design and management of the programs. In the case of SLHCs, the services are physically accessible, because they are located in or near where adolescents spend much of their waking day.

For a variety of reasons, however, a reorganization of adolescent health services to meet desirable criteria for adolescent health services has not been realized. The obstacles to reorganization are both formidable and interrelated. They include community resistance to the provision of contraceptive services and abortion counseling to adolescents; resistance of organized medicine; resistance by schools to adding yet another responsibility to the educational infrastructure; lack of a core of adequately trained professionals to staff comprehensive programs; State Medicaid administrative barriers; lack of conclusive and convincing data on the effectiveness of such programs in reducing a number of highly socially visible adolescent health problems, and, finally, lack of financing.

Policy Implications

A number of possibilities for Federal action to improve the delivery of health services to adolescents suggest themselves.

One clear need is for increased Federal attention to training of health care professionals in the area of adolescent health.

Several levels of training are important: for students at an early stage in their careers, for graduate and postgraduate students, and for professionals who are already in practice. Similarly, a range of health care professionals should be included in any increase in Federal attention to training issues at all levels of experience: nurses, psychologists, social workers, health educators, youth services workers, primary care physicians (pediatricians, internists, family physicians), and specialist physicians (e.g., obstetricians, gynecologists, dermatologists). Training should emphasize the interdisciplinary nature of work in adolescent health services. Finally, any innovations in training (or, failing innovations, current training experiences) should be subject to rigorous evaluation from a variety of perspectives, including health outcomes and patient satisfaction. Evaluations should consider not only the clinical ability of providers to identify and manage specific problems, but their adolescent-specific interpersonal skills.

Improvements in the skills of health care providers would be of benefit whether or not any other changes in the health care delivery system for adolescents were made. To improve adolescents' access to appropriate health and related services, Federal support for the reorganization of the delivery of health services to adolescents may be necessary. Increasingly, States and private foundations have seen the value in making comprehensive, integrated, approachable services immediately accessible to adolescents. However, States are increasingly strapped for money to dedicate to health and other human services (270a). Foundation funding is typically time-limited. The Federal Government could provide seed money to States, communities, health care organizations, or schools that wish to implement either school-linked or community-based centers that offer comprehensive adolescent health care. For those comprehensive adolescent health centers that exist but are in danger of losing their funding, the Federal Government could create a mechanism to help provide continuation funding, perhaps through a matching grant program.

In addition, or alternatively, either Congress or the U.S. executive branch could address, through legislation or regulation, existing barriers to the delivery of comprehensive services in adolescent health centers. These barriers include, but may not be limited to, State Medicaid administrative barriers limiting or prohibiting reimbursement for services delivered in SLHCs; and State and Medicaid restrictions on reimbursement of nonphysician providers. A study (e.g., by the U.S. General Accounting

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[113] Not all services are available at all centers. Referral and integration of services is an extremely important aspect of providing appropriate care for adolescents (34).

Office) specifying such limitations might be useful before Congress took action.

Federal support for evaluation research on a range of comprehensive adolescent health care centers would also be useful. As described in this chapter, although there is a considerable body of very valuable anecdotal and clinical knowledge that can be used to guide improvements in health care delivery for adolescents, the systematic knowledge base concerning the most effective ways to structure and deliver health services to adolescents is extremely limited. Collection, dissemination, and utilization of specific additional information can only help to improve the health care system, not only for adolescents, but for other Americans as well.

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Chapter 16

FINANCIAL ACCESS TO HEALTH SERVICES

Introduction

Financial issues are of paramount importance in any discussion of U.S. adolescents' access to health services. It is well established that health insurance coverage and ability to pay may determine when—or even whether—a person in this country seeks medical services (47,60,65). It has also been shown that while individuals in households with incomes below the poverty level have significantly fewer physician contacts than others in the same state of health, Medicaid coverage can help mitigate the effects of poverty on access to care (55).

This chapter explores the health insurance status of U.S. adolescents and addresses the following questions:

- How many adolescents are without health coverage and why are some adolescents insured and others not?
- Has the number of uninsured adolescents changed over time? If so, why has this change occurred?
- What are the benefits of private health insurance particularly for adolescent health needs?
- Who is eligible for Medicaid and what coverage does Medicaid provide?
- How many adolescents would be affected by three potential approaches to reducing the number of uninsured: a mandate that employers provide health insurance to their workers (and their dependents), an expansion of the Medicaid program, or a combination of the two?

Adolescents Without Health Insurance[1]

How Many Adolescents Lack Health Insurance and Who Are They?

In 1988, about 4.6 million U.S. adolescents ages 10 through 18—15 percent overall—had no public or private health coverage.[2] The percentage of uninsured U.S. adolescents rose nearly 5 percent from the previous year, paralleling an overall increase in the Nation's nonelderly population without health insurance. The decline in coverage among adolescents and nonelderly adults in 1988 primarily results from a drop in the percentage of the population with private health insurance, particularly among those with coverage provided by small businesses employing fewer than 100 employees. U.S. adolescents who have health insurance are more than twice as likely as 25- to 54-year-olds to be covered by Medicaid.[3]

According to data from the Current Population Survey, there was a 25-percent increase in the percentage of adolescents without health insurance between 1979 and 1986 (see figure 16-1). Trends in adolescents' health insurance status from 1979 through 1986 are briefly discussed in box 16-A. (In 1988, the health insurance section of the Current Population Survey questionnaire was modified substantially; therefore survey data from 1979 through 1986 cannot be compared with more recent statistics.)

Sociodemographic Characteristics of Uninsured Adolescents

Ninety-four percent of U.S. adolescents ages 10 to 18 live with their parents.[4] Eleven percent of U.S. adolescents live with parents who do not have health insurance (see figure 16-2), and 63 percent of

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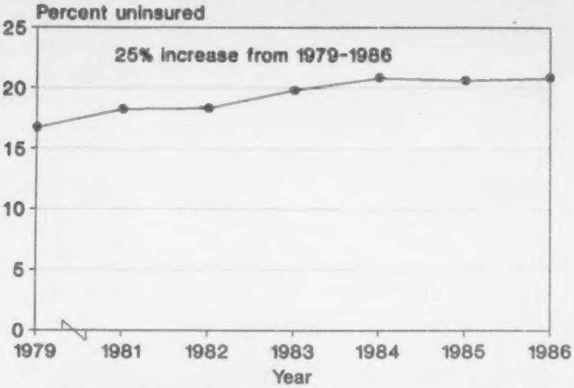
[1] Data for this analysis come from Current Population Surveys fielded in 1980 to 1989 by the U.S. Bureau of the Census (77). Each March, a supplement to the survey asks a variety of questions about work history and income during the previous year, and includes a set of health insurance questions. Responses to these questions are the basis for the analyses presented in this section. For a more in-depth analysis of these issues, see the July 1989 OTA background paper prepared by R. Kronick, *Adolescent Health Insurance Status: Analyses of Trends in Coverage and Preliminary Estimates of the Effects of an Employer Mandate and Medicaid Expansion* (44).

[2] Estimates on the number of adolescents without health insurance were developed by R. Kronick for OTA and are based on U.S. Census Bureau's Current Population Survey data (44,45).

[3] The individuals at greatest risk for being uninsured are 19- to 24-year-olds (44).

[4] This figure includes adolescents living with two parents (70 percent), adolescents living with their mother only (21 percent), and adolescents living with their father only (3 percent) (44). Adolescents living with two parents do not necessarily live with their biological parents.

Figure 16-1—Trends in the Percentage of U.S. Adolescents Ages 10 to 18 Without Health Insurance, 1979-86[a]



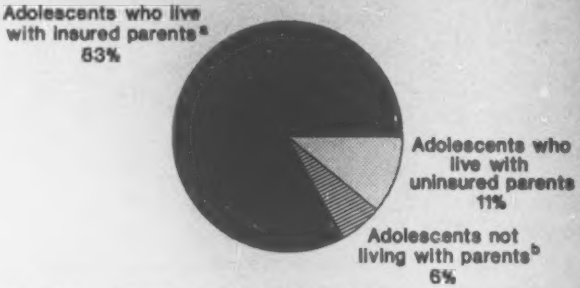
[a]In 1988 the Current Population Study questionnaire was modified substantially; therefore, survey data from 1979 through 1986 cannot be compared with more current data.

SOURCE: R. Kronick, *Adolescent Health Insurance Status: Analyses of Trends in Coverage and Preliminary Estimates of the Effects of an Employer Mandate and Medicaid Expansion—Background Paper* (Background Paper for OTA's Project on Adolescent Health), prepared under contract to the Carnegie Council on Adolescent Development and Carnegie Council of New York, for the Office of Technology Assessment, U.S. Congress, OTA-BP-H-56 (Washington, DC: U.S. Government Printing Office, July 1989).

uninsured adolescents live with parents who are also uninsured (see figure 16-3). To a large extent, then, the problem of uninsured adolescents is related to the problem of uninsured parents.

Family income is the most important determinant of health insurance status for all age groups. Those who are poor, regardless of other factors, are the most likely to be uninsured. Adolescents in poor or near-poor families[5] are much more likely to lack health insurance than others; one-third of them are without any coverage whatsoever (see table 16-1). In contrast, only 14 percent of adolescents in families with income at between 150 and 299 percent of the Federal poverty level and 4 percent of adolescents in families at 300 percent of poverty or above are uninsured.

Figure 16-2—Percentages of U.S. Adolescents Who Live With Insured Parents,[a] Uninsured Parents, or No Parents,[b] 1988

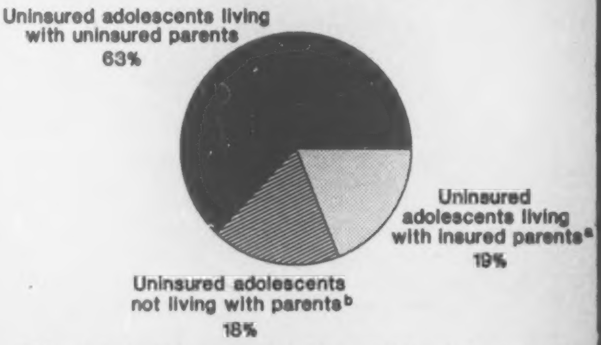


[a]This figure refers to the health insurance status of household head unless only the spouse had employment-based health coverage.

[b]This category includes adolescents not living with their parents and married adolescents living with their parents.

SOURCE: R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

Figure 16-3—Distribution of Uninsured Adolescents, by Parent's Health Insurance Status, 1988[a]



[a]Refers to the health insurance status of household head unless only the spouse had employment-based health coverage.

[b]This category includes adolescents not living with their parents and married adolescents living with their parents.

SOURCE: R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

Despite the strong relationship between poverty and the likelihood of being uninsured, it is by no means true that all the uninsured adolescents are poor. About two-thirds of uninsured adolescents live in families with incomes above the Federal poverty level: 33 percent of uninsured adolescents live in families with incomes between 100 and 199 percent of the Federal poverty level, and 29 percent live in families with incomes at 200 percent of poverty or above.[6] [7]

Several demographic characteristics have fairly strong relationships with health insurance status

---

[5]*Poor* families are those with incomes below 100 percent of the Federal poverty level, and *near-poor* families are those with incomes between 100 and 149 percent of the Federal poverty level.

[6]Percentages do not total 100 percent owing to rounding.

[7]The Federal poverty level for a family of three was $10,560 in January 1990.

Box 16-A—Analysis of Trends in Adolescent Health Insurance Status, 1979-86

From 1979 through 1986, the percentage of American adolescents without any health insurance increased by 25 percent. In the early 1980s, the rise in the percentage of uninsured adolescents was strongly associated with increased poverty and a decline in Medicaid coverage of the poor and near-poor. Later, in the mid-1980s, as the country recovered from recession, these trends improved slightly; however, the percentage of the adolescent population at each income level with private insurance declined substantially. For a combination of reasons (including a decline in the absolute number of 10- to 18-year-olds from 1979 to 1986), there was no change in the aggregate number of uninsured adolescents.

The decline in Medicaid coverage of adolescents from 1979 to 1986 was greatest among adolescents living in or near poverty. This decline was due in part to Federal regulations, issued under the 1981 Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35), that limited the working poor's eligibility for Aid to Families With Dependent Children (AFDC) and Medicaid benefits. Also, because many States did not adjust the income eligibility standards for inflation, the income threshold as a percentage of the Federal poverty level deteriorated substantially. In 1979, 48 percent of adolescents living in families with incomes between 50 to 99 percent of the poverty level had Medicaid coverage.[1] By 1983, this figure had dropped to 38 percent, but it rebounded slightly to 42 percent in 1984 and 1986. Meanwhile, almost half of the adolescents in families with incomes from 100 to 149 percent of poverty who were in the Medicaid program in 1979 had lost coverage by 1982.

The decline in private health insurance coverage of adolescents from 1979 to 1986 was also most significant among the poor. In 1979, 17 percent of adolescents in families with incomes below 50 percent of the poverty level were covered by some form of private insurance; by 1986, only 11 percent were enrolled in a private health plan. Adolescents in families with incomes between 50 to 99 percent of poverty experienced a similar trend; the proportion with private health coverage dropped from 27 to 22 percent during the same time period.

Eighteen percent of the overall rise in the percentage of U.S. adolescents without health coverage from 1979 through 1986 was due to a fall in the coverage rate among adolescents not living with any parent. In 1979, 61 percent of these adolescents were uninsured; by 1986, the figure had increased to 74 percent.

A principal reason why more U.S. adolescents were uninsured in 1986 than in 1979 is simply that more adolescents lived with uninsured parents in 1986 than in 1979. During the period 1979-86, the percentage of adolescents who lived with uninsured parents increased from 8.8 to 10.5 percent, accounting for 37 percent of the overall 1979-86 increase in the percentage of uninsured adolescents. At the same time, the percentage of uninsured adolescents who lived with uninsured parents also rose, increasing from 92 to 96 percent (contributing an additional 10 percent to the overall climb in the uninsured). The percentage of adolescents who obtained health insurance from their own jobs declined precipitously.

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[1] The method used here to determine family income and poverty status differs slightly from the calculations used by the U.S. Bureau of the Census and affects those adolescents who live in a "subfamily," for example, an unmarried 18-year-old female and her child who reside with the 18-year-old's parents. The Census method for determining family income would consider this family unit as a 4-person family and count the 18-year-old's income as well as her parents' in calculating total family income and poverty status. The results reported here treated the 18-year-old as a separate family unit and did not count her parents' income in determining total family income. Consequently, the above estimates of the percentage of adolescents living in poverty are slightly higher than Census Bureau reports. However, the differences are minor and do not affect any substantive conclusions. Note that the Census methodology is used for all other poverty and family income estimates present in this chapter.

SOURCE: R. Kronick, *Adolescent Health Insurance Status: Analyses of Trends in Coverage and Preliminary Estimates of the Effects of an Employer Mandate and Medicaid Expansion—Background Paper* (Background Paper for OTA's Project on Adolescent Health), prepared under contract to the Carnegie Council on Adolescent Development and Carnegie Corporation of New York, for the Office of Technology Assessment, U.S. Congress, OTA-BP-H-56 (Washington, DC: U.S. Government Printing Office, July 1989).

independent of family income. These include Hispanic ethnicity, parent's education, parental self-employment, and region. Hispanic adolescents are much more likely than others to be uninsured, regardless of family income. This may be because Hispanics are more likely than others to work in agriculture and domestic service, where coverage rates are historically low. If Hispanic families living in poverty are more likely than others to include both husband and wife, they will be less likely to be eligible for Medicaid. In addition, Hispanic adolescents who are undocumented immigrants are not eligible for Medicaid.

- Although black adolescents are much more likely than whites to live in or near poverty and

Table 16-1—Health Insurance Status of U.S. Adolescents Ages 10 to 18, by Family Income, 1988

Family income as a percent of the Federal poverty level[a]	Proportion of all adolescents at the specified poverty level[b]	Health insurance status: Lack health insurance coverage	Have health insurance: Private only	Have health insurance: Medicaid only	Other[c]	Total
Less than 50 percent	7.8%	29.8%[d]	13.7%	51.1%	5.3%	100.0%
50 to 99 percent	9.1	35.8[d]	21.4	36.4	6.5	100.0
100 to 149 percent	9.8	30.9	47.9	13.3	7.9	100.0
150 to 199 percent	9.7	19.8	68.6	5.0	6.6	100.0
200 to 299 percent	20.1	11.9	79.4	1.2	7.4	100.0
300 percent and above ...	43.4	4.6	0.6	0.6	5.4	100.0
	100.0%					

[a] In 1988, the Federal poverty level was $9,431 for a family of three.

[b] There were 30.8 million adolescents, ages 10 to 18, in 1988.

[c] Other includes the Civilian Health and Medical Program of the United States, Medicare, or a combination of public and private coverage.

[d] Overall, one-third of adolescents living in poverty had no health insurance.

SOURCE: R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

to be uninsured, the correlation between race and lack of health insurance coverage almost disappears when family income is taken into account.

- At each income level, adolescents whose parents have little formal education are much more likely to be uninsured than adolescents whose parents have had more education.
- Among adolescents in middle- and upper-income families, those whose parents are self-employed are much more likely than others to be uninsured.
- Adolescent children of parents who work for small firms (under 25 employees) are more likely to be uninsured than dependents of other working parents.
- More than 1 of 5 Southern and Western adolescents are uninsured, while less than 1 of 10 Northeastern and Midwestern adolescents are without coverage.

Reliable data on adolescents' health insurance status by State are not available, but estimates of the overall nonelderly uninsured population in each State are good indicators of the percentage of adolescents without coverage (see figure 16-4; table 16-2). The percentage of nonelderly people who lack health insurance among the States ranges from about 8 percent in Rhode Island to more than 26 percent in New Mexico.[8]

Further analysis shows that regional variations in health insurance coverage among adolescents are due primarily to differences in income-specific rates of Medicaid and private health coverage.[9] In the South, it appears that more stringent Medicaid income eligibility requirements are key to the greater percentage of uninsured adolescents. If income limits for Medicaid eligibility were as high in the South as in the North, the percentage of Southern adolescents without health coverage would drop by approximately 25 percent.[10] In the West, lower rates of private coverage appear to be the most critical factor, although lower Medicaid coverage rates are important as well. If income-specific rates of private insurance coverage were as high in the West as in the North, the percentage of uninsured Western adolescents would be reduced by about 19

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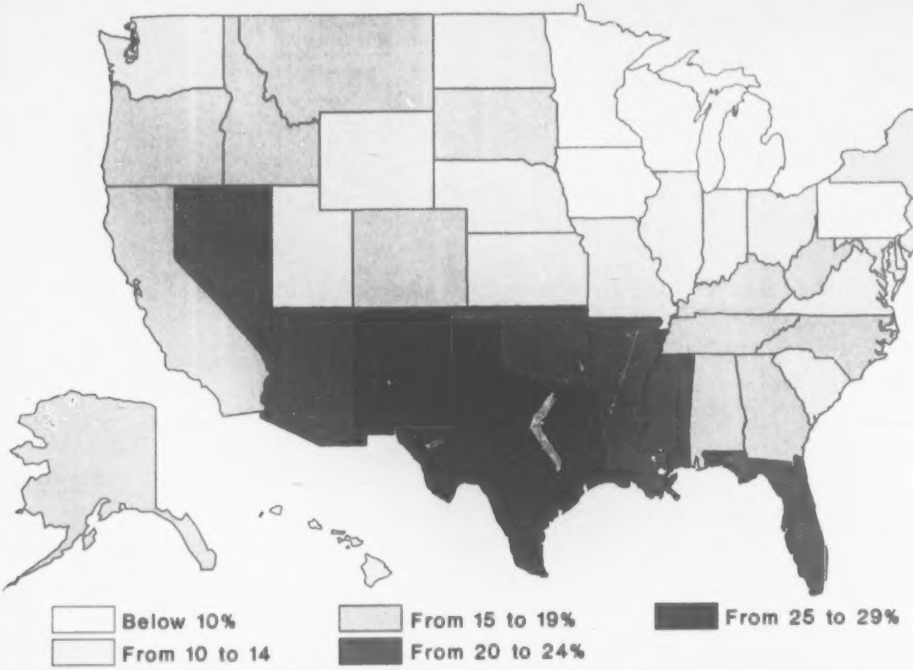
[8] These estimates were drawn from combined March 1988 and March 1989 Current Population Surveys and were calculated by Richard Kronick for OTA. Current Population Surveys' sampling precludes developing reliable estimates for the adolescent population alone.

[9] The U.S. census regions are defined as follows: *North* includes Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont; *Midwest* includes Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin; *South* includes Alabama, Arkansas, Delaware, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia; and *West* includes Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming (76).

[10] It is important to note that this analysis examined the effects of applying Medicaid income standards used in Northern States to Southern States but did not consider how the cost of living differs between the two regions. Obviously, an income of $1,500 in Mississippi, for example, would not have the same value in New York.

Figure 16-4—Percentage of the Nonelderly Population Without Health Insurance, by State, 1987-88[a]



[a]Rates are rounded to the nearest whole number. See table 16-2 for actual data, standard errors, and confidence intervals.

SOURCE: R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1988 and March 1989 Current Population Survey public use files, 1990.

percent. These results make clear that public policies designed to expand health insurance coverage—e.g., mandating employers to provide coverage or expanding Medicaid—would have markedly different regional effects. The effects in Western and Southern States would be quite different from the effects in the North. ◆

Adolescents With Private Health Insurance or Medicaid: What Coverage Provides

Adolescents with health insurance coverage, whether private or public, do not always have benefits for some of the health services they need. This section describes the benefits of both private health insurance and Medicaid. The emphasis is on those services most likely to be used or needed by adolescents, such as mental health care, substance abuse treatment, maternity care and related services, preventive services, services provided by nonphysician providers, dental care, and others.[11]

An important caveat to this review relates to the question of confidentiality in adolescent health care. Even if appropriate benefits are available, adolescents who are concerned about confidentiality may be reluctant to seek care from providers if their private health plan requires parents to submit a claim for reimbursement (as most do). An adolescent with Medicaid coverage who must present a parent's Medicaid card to gain access to care faces the same dilemma.[12] [13]

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[11] This section should not be taken as an endorsement of specific services. Much of the remainder of OTA's adolescent health Report is devoted to analyzing the effectiveness of various services. See especially Vol. II of this Report.

[12] In five States (i.e., California, Kansas, Maryland, New Hampshire, and New York), adolescents who are dependents living in families that receive Medicaid are given their own Medicaid card.

[13] For further discussion of confidentiality issues in adolescent health care, see ch. 17, "Consent and Confidentiality in Adolescent Health Care Decisionmaking," in this volume.

Table 16-2—Health Insurance Status of the Nonelderly Population, by State, 1987-88[a]

	Health insurance status								
				Have health insurance					
	Lack health insurance coverage (in rank order)		95 percent confidence intervals[b]	Private only		Medicaid only		Other[c]	
Rhode Island	8.1%	(0.010)	6.1-10.0%	79.3%	(0.015)	5.8%	(0.008)	6.8%	(0.009)
Massachusetts	8.4	(0.005)	7.4-9.3	79.7	(0.007)	6.8	(0.004)	5.1	(0.004)
Wisconsin	8.7	(0.009)	6.9-10.4	82.4	(0.012)	5.4	(0.007)	3.6	(0.006)
Minnesota	8.8	(0.009)	6.9-10.6	79.9	(0.013)	7.6	(0.009)	3.7	(0.006)
Iowa	8.8	(0.009)	7.0-10.6	82.3	(0.012)	5.7	(0.007)	3.2	(0.006)
Michigan	8.8	(0.005)	7.9-9.8	75.9	(0.007)	8.8	(0.005)	6.5	(0.004)
Pennsylvania	8.9	(0.005)	8.0-9.9	80.4	(0.007)	6.1	(0.004)	4.6	(0.004)
Connecticut	9.0	(0.010)	7.0-11.0	84.2	(0.013)	3.0	(0.006)	3.7	(0.007)
North Dakota	9.7	(0.009)	8.0-11.5	79.1	(0.012)	2.5	(0.005)	8.7	(0.009)
New Jersey	9.8	(0.005)	8.8-10.8	82.1	(0.007)	4.9	(0.004)	3.2	(0.003)
Ohio	10.1	(0.005)	9.1-11.1	76.9	(0.007)	8.0	(0.005)	5.0	(0.004)
Hawaii	10.3	(0.010)	8.3-12.3	70.0	(0.015)	3.4	(0.006)	16.3	(0.012)
Maryland	10.6	(0.010)	8.7-12.5	74.7	(0.014)	6.5	(0.008)	8.2	(0.009)
Maine	10.6	(0.010)	8.6-12.7	73.2	(0.015)	8.6	(0.009)	7.6	(0.009)
Delaware	11.1	(0.011)	9.0-13.2	76.3	(0.015)	5.6	(0.008)	7.0	(0.009)
Kansas	11.1	(0.010)	9.2-13.1	80.3	(0.013)	2.6	(0.005)	6.0	(0.008)
Illinois	11.3	(0.006)	10.2-12.4	75.1	(0.008)	9.1	(0.005)	4.6	(0.004)
Vermont	11.5	(0.011)	9.3-13.8	78.1	(0.015)	4.7	(0.008)	5.7	(0.008)
Nebraska	11.6	(0.010)	9.7-13.6	75.6	(0.013)	4.9	(0.007)	7.9	(0.008)
New Hampshire	12.1	(0.012)	9.8-14.3	81.6	(0.014)	1.0	(0.004)	5.4	(0.008)
Virginia	12.4	(0.010)	10.5-14.3	70.9	(0.013)	5.2	(0.006)	11.6	(0.009)
Missouri	12.6	(0.011)	10.5-14.7	76.0	(0.014)	6.8	(0.008)	4.5	(0.007)
New York	12.8	(0.005)	11.8-13.8	71.3	(0.007)	11.0	(0.005)	5.0	(0.003)
Utah	13.3	(0.011)	11.2-15.3	78.8	(0.013)	3.6	(0.006)	4.3	(0.006)
Washington	13.3	(0.011)	11.1-15.5	72.9	(0.015)	6.1	(0.008)	7.7	(0.009)
South Carolina	13.9	(0.011)	18.8-15.9	71.0	(0.014)	6.6	(0.008)	8.6	(0.009)
Indiana	13.9	(0.011)	11.8-16.0	77.2	(0.013)	3.6	(0.006)	5.2	(0.007)
Wyoming	14.1	(0.013)	11.6-16.7	75.1	(0.016)	3.8	(0.007)	6.9	(0.010)
North Carolina	14.9	(0.006)	13.7-16.1	73.3	(0.008)	4.2	(0.003)	7.7	(0.005)
South Dakota	15.4	(0.010)	13.4-17.4	73.3	(0.013)	4.4	(0.006)	6.9	(0.007)
Colorado	15.5	(0.013)	13.0-17.9	70.9	(0.016)	5.2	(0.008)	8.5	(0.010)
West Virginia	15.9	(0.013)	13.4-18.4	65.9	(0.016)	11.4	(0.011)	6.8	(0.009)
Tennessee	16.0	(0.012)	13.6-18.3	69.3	(0.015)	8.3	(0.009)	6.5	(0.008)
Georgia	16.5	(0.011)	14.3-18.8	68.5	(0.014)	6.9	(0.008)	8.1	(0.008)
Oregon	17.1	(0.014)	14.4-19.8	72.1	(0.016)	5.9	(0.009)	4.9	(0.008)
Montana	17.2	(0.012)	14.8-19.7	67.5	(0.015)	7.6	(0.009)	7.7	(0.009)
Idaho	17.3	(0.012)	14.9-19.6	72.9	(0.014)	3.7	(0.006)	6.1	(0.008)
Kentucky	17.5	(0.013)	15.0-20.0	67.9	(0.016)	7.9	(0.009)	6.7	(0.009)
District of Columbia	18.4	(0.014)	15.7-21.1	66.3	(0.017)	10.4	(0.011)	4.9	(0.008)
Alaska	18.5	(0.012)	16.1-20.9	56.6	(0.016)	8.3	(0.009)	16.6	(0.012)
Alabama	18.8	(0.014)	16.2-21.5	66.6	(0.016)	8.5	(0.010)	6.1	(0.008)
California	19.4	(0.006)	18.3-20.6	64.2	(0.007)	9.2	(0.004)	7.1	(0.004)
Nevada	20.3	(0.014)	17.5-23.1	68.4	(0.016)	2.9	(0.006)	8.4	(0.010)
Mississippi	20.7	(0.013)	18.2-23.3	59.2	(0.016)	11.4	(0.010)	8.7	(0.009)
Arizona	20.9	(0.014)	18.3-23.6	67.8	(0.016)	3.1	(0.006)	8.2	(0.009)
Florida	21.2	(0.007)	19.9-22.5	65.1	(0.008)	5.1	(0.004)	8.6	(0.005)
Oklahoma	21.9	(0.013)	19.3-24.5	63.0	(0.016)	6.0	(0.008)	9.1	(0.009)
Louisiana	22.3	(0.014)	19.6-25.0	59.5	(0.016)	12.6	(0.011)	5.6	(0.008)
Arkansas	22.6	(0.014)	20.0-25.3	61.2	(0.016)	9.6	(0.010)	6.6	(0.008)
Texas	24.8	(0.007)	23.4-26.0	62.6	(0.008)	5.4	(0.004)	7.2	(0.004)
New Mexico	26.3	(0.014)	23.6-28.9	55.8	(0.015)	7.0	(0.008)	11.0	(0.010)

[a] Results in parentheses are standard errors.

[b] Confidence intervals for estimates of the proportion of the State population without health insurance.

[c] Other includes the Civilian Health and Medical Program of the United States, Medicare, or any combination of public and private coverage.

SOURCE: R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1988 and 1989 Current Population Survey public use files, 1990.

Private Health Insurance Coverage[14]

About 21.7 million U.S. adolescents ages 10 through 18 (70 percent) are covered by private health insurance (44). What follows is a review of recent trends in private health insurance coverage, the limitations of existing data sources on current health benefits, the general nature of health insurance coverage, and an analysis of benefits provided by private health plans.

Trends in Private Health Insurance Coverage

The nature of private health insurance coverage changed dramatically in the 1980s, and the 1990s promise more change. Taking note of some of these trends is important because they have a direct effect on what private health benefits provide. One striking development has been the growth of self-insurance among the Nation's employers, largely due to the passage of the Employee Retirement and Income Security Act (ERISA) (Public Law 92-104) in 1974.[15] ERISA freed self-insured plans from State health insurance regulations including State premium taxes and State mandates to insurers to provide minimum coverage for specific services, categories of providers, diseases, or individuals who might have difficulty in obtaining coverage (13,27).[16] There is some evidence that many employers have chosen to self-insure to escape the costs and administrative burden of conforming with State mandates (28). It is not clear whether mandates are the principal cause of the shift to self-insurance, but it is certain that the potential pool of health plans that might be affected by mandates has greatly diminished. From the time of ERISA's enactment in 1974 to 1987, the percentage of employees covered by a self-insured employer-sponsored conventional health plan rose from about 5 percent to nearly 60 percent (26).

Since the 1970s, many States have enacted mandates expanding the health insurance benefits provided by traditional commercial health insurers and Blue Cross and Blue Shield plans.[17] Between 1978 and 1988, the number of State-mandated benefits grew from 343 to 732 (28). There is now growing concern that the onus of providing ever more comprehensive coverage has contributed to growth in the population of the uninsured, particularly among workers (and their dependents) in small businesses (42). This concern is reflected in the growing number of States that have passed laws requiring evaluation of the social and financial impact of mandated health insurance benefits (39).

The way dependents are covered by employment-based health plans is changing, and there is reason to be concerned that increasingly higher premium costs for family coverage combined with greater cost-sharing for dependent coverage may lead to more uninsured adolescents and other family dependents. About 47 cents of every dollar of health care expense incurred by privately insured employees is reported to be for the treatment of dependents (57). The average monthly cost of family health coverage exceeded $260 in 1989 (parents paid an average share of $55 to $81 per month for the entire family depending on the type of plan) and was approximately 18 percent higher than the previous year (36). The ever-increasing cost of health benefits, in general, and dependent care, in particular, has recently moved employers to require parents to pay a larger portion of their health insurance premiums and to share more of the costs for their dependents (9,15,67). From 1980 to 1988, the percentage of participants, in medium and large private group health plans, required to contribute for family coverage increased from 46 to 63 percent (15). The U.S. General Accounting Office, in a 1988 investigation of the effects of cost increases on health coverage, found that "some firms provide little or no contribution to dependent coverage" and "for lower-income families, the high cost of family coverage can lead to decisions to forgo dependent coverage"(66). Meanwhile, some employers are planning to restrict or exclude dependent coverage, especially for mental health or substance abuse, while retaining the benefits for their own employees (9,57).

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[14] In this discussion, the terms private health insurance, private health plans, and group health plans are often used interchangeably to refer to employment-based group plans regardless of sponsorship or financing arrangement (i.e., conventional plans, self-insured plans, health maintenance organizations, etc).

[15] A *self-insured plan* is a health benefit plan in which the financial risk for provided medical services is assumed by the employer or sponsor.

[16] A *conventional health plan* is a traditional indemnity or fee-for-service health plan that typically reimburses the health provider on a "reasonable and customary" basis or as billed.

[17] It is important to be aware that health coverage provided by self-insured employers, health maintenance organizations (HMOs), and individual family plans are usually not affected by State mandates. HMOs are often regulated independently from indemnity carriers and, as noted, self-insured plans are exempt from State insurance regulations. HMOs may be subject to their own mandated benefit rules.

Equally important has been the rapid growth in *managed* health care. In 1987, more than 60 percent of Americans with group health insurance coverage were enrolled in a health maintenance organization (HMO), preferred provider organization (PPO), or a managed fee-for-service health care plan (27).[18] Patients in managed health care plans do not have open access to physicians or hospitals and usually must obtain prior approval before admission to a hospital. HMOs and PPOs may also require that the health provider's treatment plan be reviewed to ensure that the hospital care is necessary. Patients who do not follow the HMO or PPO guidelines may face larger out-of-pocket costs or be denied payment altogether (13). On the other hand, case management may allow for more flexibility in the care of high-cost illnesses. Some managed health care plans contain "individual benefits management" programs that allow for payment of otherwise *uncovered* benefits, such as home- and community-based services, in order to avoid more costly *covered* services (24).

Limitations of Data on Private Health Insurance

Comprehensive national data on benefit coverage are fairly limited. Survey data are the principal source of information on benefit coverage and have several key limitations.[19] Surveys of benefits are often confined to health plans provided by medium and large private employers and thus do not reflect coverage offered by small employers and nongroup family plans that are almost always *less* comprehensive and generous than others (41).[20] To date there have been no surveys of private health benefits that have focused on adolescent needs in particular. Because available surveys examine benefits in general and do not report whether equivalent dependent coverage is available, this review must assume that survey findings apply to both the subscriber and his or her dependents. A notable exception, however, is maternity care, which often is provided only to the policyholder and spouse.[21]

What Private Health Insurance Coverage Provides

Group health plans have traditionally served as protection against the major costs of hospital and physician-provided services for the care of acute illness. Most Americans who participate in an *employment-based* group health plan have benefits for a wide range of hospital and medical services particularly if the subscriber works for a medium or large employer. Health benefits surveys by the Bureau of Labor Statistics and the Health Insurance Association of America show that 90 percent or more of employees with employer-based group health coverage have health benefits for hospital room and board, surgical services, physician visits (i.e., for the diagnosis, evaluation, and treatment of an illness or injury), diagnostic X-ray and laboratory procedures, outpatient prescription drugs, mental health, and substance abuse (see table 16-3). Other medical care services, such as routine physical exams, preventive diagnostic procedures (e.g., pap smears), vision, hearing, dental, home health, and extended care are less likely to be covered (see table 16-3) (31,32,84).

Most conventional private health plans require annual deductibles and coinsurance payments before

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[18] *Health maintenance organizations* (HMOs) are entities that act as both insurer and provider of comprehensive but specified medical services in return for prospective, periodic per capita payments. *Preferred provider plans* (PPOs) are groups of health providers that contract with employers, insurers, third-party administrators, or other sponsoring groups to provide services on a discounted fee-for-service basis; health plan participants who use these providers pay lower deductible and coinsurance payments. A *managed fee-for-service health care plan* is a conventional health plan which requires patients to obtain prior approval before admission to a hospital and prospective utilization review.

[19] Two surveys serve as the principal data sources for this discussion. The most representative of employment-based group coverage is the Health Insurance Association of America's 1988 survey of 1,665 randomly selected employers who offer health insurance to their employees (32). This sample represents an estimated 84 percent of those who receive employment-based health insurance from small, medium, and large firms in the private and public sectors. Interviews were conducted by telephone. Federal employees and individuals who obtain their own insurance were not included (32). Another survey, although not representative of small firms, is the U.S. Department of Labor annual survey of employee benefits in medium and large firms that is conducted by the Bureau of Labor Statistics (84,85). In 1988, the Bureau of Labor Statistics survey included a stratified sample of 1,922 private, nonfarm establishments employing at least 100 employees (84). Data for the survey were drawn from health plan documents collected by Bureau field representatives and analyzed by Bureau staff in Washington (84).

[20] Medium and large firms are generally those with at least 100 or 250 employees, depending upon the industry, and represent approximately 49 percent of the Nation's work force (8). *Nongroup family plans* refer to health insurance plans that are purchased on an individual basis and are not obtained through an employment or other membership group contract. Approximately 10 to 12 percent of individuals covered by private health insurance are in a nongroup individual or family plan.

[21] Many privately insured adolescents are not eligible for coverage, in part because of a "loophole" in the Pregnancy Discrimination Act of 1978 (Public Law 95-555). See "Maternity Care and Related Services," below.

Table 16-3—Two Surveys' Estimates of the Percentage of Participants in Employment-Based Group Health Insurance With Some Coverage for Selected Benefits, 1988[a]

Category of medical care	Survey[b]	Estimate of percentage with coverage	Category of medical care	Survey[b]	Estimate of percentage with coverage
Diagnostic X-ray and laboratory	BLS	98%	Prescription drugs[e]	HIAA	93%
Hospital room and board	BLS	98	Treatment for substance abuse[f]	HIAA	90
Surgical services			Home health care[g]	HIAA	86
Inpatient	BLS	98	Extended care facility[g]	HIAA	79
Outpatient[c]	BLS	98	Preventive diagnostic procedures	HIAA	69
Physician visits			General dental care[e]	HIAA	37
In hospital	BLS	98	Vision[e]	BLS	35
In office	BLS	98	Immunization and inoculation	BLS	29
Mental health[d]			Routine physical exams	BLS	28
Outpatient care	HIAA	95	Hearing	HIAA	27
Hospital care	HIAA	98	Orthodontia[e]	HIAA	27

[a] Note that employment-based group health coverage is the most comprehensive form of health insurance. Details on the scope of coverage offered by nongroup family plans is very limited, although typically such plans are known to be less generous.

[b] Estimates are drawn from 1988 surveys conducted by either the Health Insurance Association of America (HIAA) or the Bureau of Labor Statistics (BLS). Data from the HIAA survey are provided when available as they are more representative of employment-based group coverage; the HIAA sample includes 1,665 randomly selected employers and reflects an estimated 84 percent of those who receive employment-based health insurance from small, medium, and large firms in the private and public sectors (30). The BLS survey includes a stratified sample of 1,922 private, nonfarm establishments employing at least 100 employees (77).

[c] Charges incurred in the outpatient department of a hospital and outside of the hospital.

[d] Benefits for mental health problems, including diagnosable mental disorders, almost always are more limited than for "physical" health problems. Benefits are often subject to one or more of the following restrictions that are separate from other medical coverage: a limited allowance of hospital days (e.g., 30 per lifetime) and/or number of outpatient visits, a maximum ceiling on total dollars reimbursed, a higher coinsurance rate (e.g., 50 percent), no ceiling on out-of-pocket expenses, and a separate copayment or deductible.

[e] Benefits are typically subject to limitations such as scheduled dollar allowance and deductibles, copayments, and coinsurance requirements that are separate from other covered benefits.

[f] Substance abuse benefits are almost always more limited than for "physical" health problems. Coverage is usually subject to separate limitations including a limited allowance of hospital days for detoxification or rehabilitation, a restricted number of outpatient visits, a maximum ceiling on total dollars reimbursed, a higher coinsurance rate, no ceiling on out-of-pocket expenses, a separate copayment or deductible, and a separate lifetime maximum.

[g] Some plans provide this care only to a patient who was previously hospitalized and is recovering without need of the extensive care provided by a general hospital. Does not include hospice care.

SOURCE: Office of Technology Assessment, 1991.

any benefits are paid; although total out-of-pocket expenses are often capped at a maximum less than $2,000 per year (32).[22] Once the insured's covered expenses exceed that amount, the health plan pays for the full cost of any subsequent covered expenses. HMO coverage is prepaid and members do not pay deductibles or coinsurance although minimal outpatient visit copayments may be required.

Preventive Services—A number of preventive services are typically recommended for adolescents: routine physical examinations, immunizations, and certain diagnostic tests (e.g., hematocrit, urinalysis) and preventive procedures including pap smears and screening for sexually transmitted diseases for the sexually active (62). The likelihood that an adolescent has preventive benefits depends largely on whether he or she is enrolled in a conventional health plan or HMO. Whether in an HMO or not, if routine physical exams are a covered benefit, coverage may be limited to a periodicity schedule such as that recommended by the American Academy of Pediatrics.[23] The 1988 Bureau of Labor Statistics survey found that only 28 percent of all participants in employer-sponsored group health plans were covered for routine physical exams, as compared with 99 percent of HMO members (84). Coverage rates for immunizations and inoculations also varied by the type of health plan: 29 percent for all participants in group health plans and 99 percent for HMO members (84).

Benefits for *preventive* diagnostic tests and procedures (e.g., pap smears, mammograms) are also related to the type of health plan and, in conventional health plans, may be linked to whether the insurer views the procedure as *diagnostic*. Coverage may depend upon whether the physician "justifies" the procedure with a specific suspected diagnosis. Benefits for *diagnostic* laboratory tests are virtually universal among medium and large employers (83). In contrast, the Health Insurance Association of America survey of employer-sponsored group health insurance found more limited coverage of *preventive* diagnostic procedures; coverage was available in 61, 72, and 98 percent of conventional, PPO, and HMO plans respectively (32).

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[22] A *deductible* is a specific dollar amount, usually about $400 per family, that must be paid before a health plan begins paying benefits. *Coinsurance payments* are a specified percentage, commonly 20 percent, that the insured must pay for each covered medical service up to an annual limit (e.g., $1,500), after which the health plan pays 100 percent of covered benefits (36,70).

[23] For a discussion of periodicity schedules for routine health assessments, see ch. 15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents," in this volume.

Mental Health Care—Although coverage of mental health services is often provided by employer-sponsored group health plans, the benefits for mental health problems, including diagnosable mental disorders, are almost always more limited than for the benefits of "physical" health problems (see table 16-4). While 98 percent of employees in group health plans provided by medium and large employers have some inpatient and outpatient mental health coverage, only 27 percent are covered for inpatient mental health as for other illnesses and only 3 percent have equivalent mental and physical health outpatient coverage (84). Mental health benefits are often subject to one or more of the following restrictions that are separate from other medical coverage: a limited allowance of hospital days (e.g., 30 per lifetime); a limited number of outpatient visits; a maximum ceiling on total dollars reimbursed; a lower coinsurance rate (e.g., 50 percent); no ceiling on out-of-pocket expenses; and a separate copayment or deductible.

These benefit restrictions clearly have a major impact on the use and overall cost of mental health services (25). In fact, the amount of mental health services and the settings in which they are provided is often determined largely by the extent of reimbursable services (38). More details on benefit limitations are described below.

Inpatient Care for Mental Health—Many mental health professionals report that inpatient mental health benefits significantly influence both hospital admissions and length of stay (49). Mental health inpatient stays are commonly limited to 30 or 60 days per year, compared with 120 or 365 days for other hospital stays (84). Among participants in employer-sponsored health plans with mental health coverage, 45 percent had separate limitations on the duration of a hospital stay for mental illness in 1988 (84).

Table 16-4—Coverage of Mental Health Care: Percent of Full-Time Participants in Plans With Coverage by Extent of Benefits, Medium and Large Firms, 1988

Coverage limitation	Inpatient mental health care	Outpatient mental health care
With coverage	98%	98%
Covered the same as other illnesses	27	3
Subject to separate limitations[a]	71	95
Limit on days or visits	45	36
Per year	36	35
Per lifetime	2	—
Coinsurance limit	8	62
50 percent	4	49
Other[b]	4	14
Ceiling on out-of-pocket expenses does not apply	13	43
Separate copayment or deductible	1	14
Not covered	2	2

[a] The total is less than the sum of the individual items because many plans had more than one type of limitation on mental health coverage.

[b] Includes plans with reduced coinsurance other than 50 percent and plans where the rate of reimbursement varied during the treatment period.

SOURCE: U.S. Department of Labor, Bureau of Labor Statistics, *Employee Benefits in Medium and Large Firms*, Bulletin 2336 (Washington, DC: U.S. Government Printing Office, 1989).

There is some evidence that limiting the number of allowable mental health days may affect adolescents and adults differently. One study of the psychiatric claims of eight companies covered by the same insurance carrier found that, given any use of mental health services, children and adolescents were much more likely than adults to be inpatient users (38). They also had significantly longer average lengths of stay, were more likely to have very long lengths of stays, and had a greater chance of incurring a catastrophically expensive psychiatric claim (38). Whether existing mental health and substance abuse benefits, which were designed principally for adults, are appropriate for adolescents is not clear. In 1986, the Oregon Health Planning and Development Agency was required by statute to evaluate the effects of a 1983 State mandate to provide insurance coverage of mental health and chemical dependency treatment. The planning agency concluded that the minimum benefit levels established for adults were "wholly inadequate for children and adolescents" (59). The following year the Oregon legislature enacted a bill requiring separate, higher benefit levels for children and adolescents age 17 and younger (58).

Many observers are also concerned that mental health benefits in private health plans that favor inpatient over outpatient or community-based care have led to inappropriate hospitalizations and overutilization of inpatient services by some adolescents (29).[24] One particularly in-depth look at this issue led the researcher to conclude in referring to State-mandated mental health benefits that "the policies of jurisdictions that seek to discourage insurance-carrier discrimination against persons suffering from mental health problems may, in fact, be perpetuating a pattern of financial incentives that is detrimental to the well-being of the population they seek to serve" (86).

Partial Hospitalization—Partial hospitalization, also known as day treatment, is an alternative to traditional inpatient and outpatient care that provides adolescents an alternative to hospitalization and a transitional level of mental health services after discharge from an inpatient psychiatric unit or residential treatment facility. It can be used for adolescents who no longer need 24-hour care but are not yet ready to reenter school (7). When partial hospitalization is available, it can help avoid institutional placement. In 1986, less than 11 percent of participants in employment-based health plans were covered for partial hospitalization (4).[25]

Outpatient Care for Mental Health—Coverage for outpatient mental health care may be limited in a variety of ways. For more than 60 percent of participants in health plans surveyed by the Bureau of Labor Statistics in 1988, reimbursement for outpatient mental health services may not exceed an annual dollar maximum (e.g., $750 to $1,000) and a coinsurance rate of 50 percent rather than the usual 20 percent per visit may be required. (The average charge for a visit to a psychiatrist was $80 in 1986 (4).) Thirty-six percent of participants in employer-sponsored health plans surveyed by the Bureau of Labor Statistics have an annual visit limit (84); more than 84 percent with visit limits are allowed more than 30 visits each year (4). An annual 50-visit maximum is most common (70). Some plans also limit visit fees (4,70). Combinations of any of these restrictions are common. The most common effect of such constraints is to cap total mental health outpatient coverage at about $2,000 a year (70).

Eligible Mental Health Providers—Many health plans may not cover mental health services that are provided by nonphysicians. One employer survey found that in 1987 only 15 percent of employers provided plans that covered the services of psychologists and psychiatric social workers in addition to psychiatrists (23).[26] However, most plans accept claims filed by a psychiatrist for services provided by another mental health professional under his or her supervision (23).

Annual and Lifetime Maximums—Annual and lifetime ceilings on payment for mental health services are a common feature of many health plans. One survey found that, among employers who limited payment for outpatient care, the average reported lifetime outpatient payment maximum was $20,000 (19). The Bureau of Labor Statistics survey found that in 1988 health plans sometimes imposed a lifetime maximum (e.g., $50,000) on all mental health benefits (84).[27] Lifetime limits on care for other types of illness are not only more rare but also significantly higher (e.g., $1 million maximum reimbursement for all covered expenses) (32).

HMOs' Mental Health Coverage—It is not known how many adolescents belong to an HMO, but it is likely that many young people rely on HMOs for their mental health as well other health care needs. In 1989, there were 491 HMOs with a total enrollment of 34.7 million (30). Almost one out of five people who are covered by a group health plan belongs to an HMO (34). A 1985 HMO survey by Interstudy found that almost all HMOs (99 percent) provide some level of mental health coverage and about one-quarter offer additional coverage at extra cost (37).[28] As they are in most conventional health plans, mental health services in HMOs are strictly controlled. The most common annual benefit limits are 30 inpatient days and 20 outpatient visits (30) but some have 30 inpatient days per lifetime. HMO copayments, however, are much less burdensome than those required by conventional health plans. Out-of-pocket payments for inpatient care are rarely required and outpatient copayments average only $15 per visit (after five free visits) (46).

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[24] For a discussion of inpatient mental health utilization by adolescents, see ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II.

[25] This figure is based on American Psychiatric Association tabulations of the 1986 Bureau of Labor Statistics employee benefits survey.

[26] This health benefits survey was conducted in 1987 by Fox Health Policy Consultants and included 150 small, medium, and large employers (23).

[27] This could easily be spent on 1 year of inpatient treatment.

[28] The Interstudy HMO survey included 247 plans that were operational for more than 1 year at the end of 1985 (40).

Yet these relatively low fees may be countered by other access controls. HMOs typically require a primary care physician to approve of specialty services, and more than three-quarters of the HMOs surveyed by Interstudy require members to receive primary care physician approval in order to gain access to mental health services (40). Twenty-one percent of the surveyed plans indicated taking a careful screening approach to "limit entrance into the HMO's mental health system." Nonetheless, 53 percent reported that they may permit self-referral. When access is controlled by a prior approval requirement, it is often limited to mental health problems that the HMO provider considers responsive to treatment within the benefit's time constraints. More than half of the surveyed Interstudy plans reported that they specifically exclude treatment of chronic mental illness, long-term psychotherapy, and psychosexual disorders from basic coverage. Another 17 percent also exclude eating disorders (40).

Current Changes in Mental Health and Substance Abuse Coverage Policy—It is important to recognize that employer and insurer attitudes toward coverage of mental health and substance abuse treatment (see below) are in flux, especially with respect to adolescents. In the last decade, utilization of benefits for mental health and substance abuse care grew dramatically, particularly among adolescents (12).[29] As benefits rapidly became widespread—coverage for treatment of alcoholism almost doubled from 36.2 percent of participants in employment-based health plans in 1981 to 70 percent in 1986—expenditures soared. Employers spent $207 per employee for mental health benefits in 1988 (14). One Blue Cross and Blue Shield plan, Independence Blue Cross of Philadelphia, experienced a 57-percent increase in admission rates for substance abuse treatment in 2 years, while its expenditures for inpatient substance abuse treatment increased more than four times, from $4 million to $18.5 million (5).

Claims for mental health and substance abuse treatment services can now make up as much as 15 to 20 percent of an employer's health care dollars—most of it for adolescents (6). One study of the health insurance claims of a large corporation found that 60 percent of mental health expenditures were for nonspouse dependents[30] (64). A study examining the experience of more than 200,000 employees covered by Metropolitan Life Insurance found the average expense per inpatient mental health admission for nonspouse dependents was $18,036 in 1988, almost twice the cost for employees and their spouses (12).[31] Inpatient treatment costs for substance abuse were also substantially higher for nonspouse dependents than for adults. As a result, many employers and health insurers are reconsidering how and whether to cover mental health and substance abuse treatment for dependents. A recent survey of corporate benefits decisionmakers found that more than half predicted restricting or excluding coverage for dependent mental health or chemical dependency illnesses (57).[32]

Substance Abuse Treatment[33]—Although health coverage for the treatment of alcoholism and drug abuse has traditionally trailed behind coverage for other illnesses, it has become much more widely available in recent years. It wasn't until the mid-1960s that limited coverage for alcoholism treatment was offered by a few commercial health insurers (50). Now the majority of participants in group health plans have some level of substance abuse benefits whether covered by a conventional plan (87 percent), an HMO (98 percent), or a PPO plan (93 percent) (32).

Coverage for both alcohol and drug abuse treatment, like that for mental health problems, is usually subject to special limitations. Employer-sponsored health plans most often cover short-term inpatient detoxification and frequently cover inpatient rehabilitation and outpatient treatment as well, though

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[29] For further discussion of adolescent mental health utilization, see ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II.

[30] Nonspouse dependents were primarily children under 19 years who have never married but also included full-time college students age 19 to 24 and any unmarried dependents who were physically handicapped or mentally retarded.

[31] Nonspouse dependents were found to be principally adolescents ages 11 to 19.

[32] This survey was conducted by the group insurance division of Northwestern National Life Insurance Co. and included 400 companies representing 3.9 million workers (57).

[33] Additional information on substance abuse treatment is presented in ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II.

Table 16-5—Coverage of Alcohol Abuse Treatment: Percent of Full-Time Participants in Plans With Coverage by Extent of Benefits, Medium and Large Firms, 1988

Coverage limitation	Inpatient detoxification[a] [b]	Inpatient rehabilitation[a] [c]	Outpatient care[a] [d]
With coverage	95%	78%	84%
Covered the same as other illnesses	29	15	17
Covered the same as mental illness	7	6	18
Subject to separate limitations[e]	59	57	49
Limit on days	46	46	24
Per year	26	27	24
Per confinement	18	16	—
Per lifetime	15	17	7
Limit on dollars	21	19	28
Per day	1	1	6
Per year	9	8	19
Per lifetime	16	15	10
Coinsurance limit[f]	6	5	13
Ceiling on out-of-pocket expenses does not apply	4	5	10
Separate copayment or deductible	1	1	6
Other limitations[g]	1	1	1
Without coverage	5	22	16

NOTE: Because of rounding, sums of individual items may not equal totals.

[a] Overall, the Bureau of Labor Statistics estimates that 80 percent of full-time participants in health plans provided by medium and large firms have alcohol abuse treatment benefits. The percents shown in this table apply to those participants who have benefits. So, for example, 95 percent of the 80 percent of those participants who have alcohol abuse benefits are covered for inpatient detoxification.

[b] Detoxification is the systematic use of medication and other methods under medical supervision to reduce or eliminate the effects of substance abuse.

[c] Rehabilitation is designed to alter abusive behavior in patients once they are free of acute physical and mental complications.

[d] This category includes treatment in one or more of the following: outpatient department of a hospital, residential treatment center, organized outpatient clinic, day-night treatment center, or doctor's office. If benefits differed by location of treatment, doctor's office care was tabulated.

[e] The total is less than the sum of the individual items because some plans contained more than one type of limitation.

[f] Coinsurance rate is lower than that applying to other medical services.

[g] This category includes plans where coverage was subject to overall deductibles or maximum dollar amounts that differed from those for other medical services.

SOURCE: U.S. Department of Labor, Bureau of Labor Statistics, *Employee Benefits in Medium and Large Firms*, Bulletin 2336 (Washington, DC: U.S. Government Printing Office, 1989).

not to the extent of other illnesses and almost always with limitations (see tables 16-5 and 16-6).[34] In 1988, among full-time participants in health plans with drug or alcohol abuse coverage, approximately 95 percent had inpatient detoxification benefits, about 78 percent had inpatient rehabilitation benefits, and 81 to 84 percent were covered for outpatient care (84).

Although benefits for substance abuse treatment may be subject to the same restrictions as mental health care, they are most often provided under their own separate limitations including a limited allowance of hospital days for detoxification or rehabilitation, a restricted number of outpatient visits, a maximum ceiling on total dollars reimbursed, a lower coinsurance rate, no ceiling on out-of-pocket expenses, a separate copayment or deductible, and a separate lifetime maximum. It appears that benefits for alcohol and drug abuse treatment are very similar; little difference in the scope of coverage for the two can be found in the results of the Bureau of Labor Statistics survey.

HMO benefits for alcohol and drug abuse treatment are as strictly controlled as they are for mental health. Almost one-third of HMOs provide benefits only for the strict purposes of detoxification and emergency drug abuse care (46). Interstudy's 1985 survey indicates that hospitalization, when provided at all, is most commonly limited to 34 days for alcohol and 36 days for drug abuse treatment (per benefit period) (37). Most plans allow 28 outpatient visits for alcohol abuse treatment while few report specific limits on ambulatory drug-related care (40).

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[34] *Detoxification* is the systematic use of medication and other methods under medical supervision to reduce or eliminate the effects of substance abuse. *Rehabilitation* is designed to alter abusive behavior in patients once they are free of acute physical and mental complications (84).

Table 16-6—Coverage of Drug Abuse Treatment: Percent of Full-Time Participants in Plans With Coverage by Extent of Benefits, Medium and Large Firms, 1988

Coverage limitation	Inpatient detoxification[a] [b]	Inpatient rehabilitation[a] [c]	Outpatient care[a] [d]
With coverage	96%	77%	81%
Covered the same as other illnesses	28	13	17
Covered the same as mental illness	7	6	18
Subject to separate limitations[e]	61	58	46
Limit on days	47	46	21
Per year	26	27	20
Per confinement	18	17	—
Per lifetime	15	16	6
Limit on dollars	21	19	27
per day	—[f]	—[f]	6
Per year	9	7	19
Per lifetime	16	16	11
Coinsurance limit[g]	7	6	13
Ceiling on out-of-pocket expenses does not apply	5	5	10
Separate copayment or deductible	1	1	6
Other limitations[h]	1	1	2
Without coverage	4	23	19

NOTE: Because of rounding, sums of individual items may not equal totals.

[a] Overall, the Bureau of Labor Statistics estimates that 74 percent of full-time participants in health plans provided by medium and large firms have drug abuse treatment benefits. The percents shown in this table apply to those participants who have benefits. So, for example, 96 percent of the 74 percent of those participants who have drug abuse benefits are covered for inpatient detoxification.

[b] Detoxification is the systematic use of medication and other methods under medical supervision to reduce or eliminate the effects of substance abuse.

[c] Rehabilitation is designed to alter abusive behavior in patients once they are free of acute physical and mental complications.

[d] This category includes treatment in one or more of the following: outpatient department of a hospital, residential treatment center, organized outpatient clinic, day-night treatment center, or doctor's office. If benefits differed by location of treatment, doctor's office care was tabulated.

[e] The total is less than the sum of the individual items because many plans had more than one type of limitation.

[f] Less than 0.5 percent.

[g] Coinsurance rate is lower than that applying to other medical services.

[h] This category includes plans where coverage was subject to overall deductibles or maximum dollar amounts that differed from those for other medical services.

SOURCE: U.S. Department of Labor, Bureau of Labor Statistics, *Employee Benefits in Medium and Large Firms*, Bulletin 2336 (Washington, DC: U.S. Government Printing Office, 1989).

Maternity Care and Related Services[35]—Although private health insurance coverage of prenatal and maternity care is generally comprehensive, many privately insured adolescents are not eligible for coverage, in part because of a "loophole" in the Pregnancy Discrimination Act of 1978 (Public Law 95-555).

Pregnancy and Childbirth—Since the enactment of the Pregnancy Discrimination Act of 1978 (Public Law 95-555), almost all employment-based health plans provide maternity care benefits (35).[36] The Pregnancy Discrimination Act, which amends the Civil Rights Act of 1964 (Public Law 88-352), requires that employment-based health plans cover pregnancy, childbirth, or related medical conditions as they cover other medical care. Nevertheless, approximately one-third of privately insured adolescents are not covered for maternity-related services by their parents' employment-based health plan (1).[37] [38]

This situation is in part due to a "loophole" in the Pregnancy Discrimination Act that affects adolescent daughters of privately insured parents more

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[35] *Maternity care* is used here to refer to prenatal, delivery, and postpartum care.

[36] Health coverage provided by small employers is an exception; approximately 11 percent of employee groups under 25 do not provide maternity care benefits. The Pregnancy Discrimination Act does not extend to nongroup policies or employees of firms with 15 or fewer employees where maternity coverage is often limited or not available at all (1).

[37] This estimate is based on the Alan Guttmacher Institute's calculations of data from the 1984 Bureau of Labor Statistics survey of employee benefits in medium and large firms.

[38] Lack of maternity coverage appears to be a critical issue for a significant proportion of the uninsured. One study found that 40 percent of hospital patients who are self-paying or not billed for care are recipients of maternity care; how many are adolescents is not clear (61).

Photo credit: March of Dimes Birth Defects Foundation

Approximately one-third of privately insured adolescents are not covered for maternity-related services by their parents' employment-based health plan.

than any other group.[39] The Pregnancy Discrimination Act's *regulations*, in referring to dependents other than spouses, state that employer-provided health "insurance does not have to cover the pregnancy-related conditions of other dependents" (29 CFR 1985 ed. 1604, App.).

In many States, the loophole can be overridden in cases of pregnancy complications. Twenty-six States mandate that regardless of whether an individual has coverage for normal pregnancy, insurers must cover pregnancy complications in the same manner as any other illness (1).[40] Thus, for an ectopic pregnancy, for example, adolescent mothers who are otherwise not eligible for maternity benefits but are privately insured through a parent's policy can get coverage for necessary care. The States typically provide some guidance to health plans as to what constitutes a complication of pregnancy but case-by-case decisions are usually made by the insurance carrier (1).

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[39] Note that 10 States (Illinois, Maine, Maryland, Massachusetts, Minnesota, New Jersey, New York, Ohio, Virginia, and Wisconsin) have mandated that the requirements of the Pregnancy Discrimination Act also extend to nonspouse dependents (e.g., adolescent mothers). (Virginia's mandate is limited to children who have been raped or females under 13 years who have been victims of rape or incest.)

[40] Note that two States limit this requirement to group policies and two others limit it to nongroup policies (1).

When a pregnant adolescent dependent has private health coverage for maternity care, she is not treated differently from any other pregnant health plan beneficiary. Maternity benefits are rarely subject to special limitations, but standard coinsurance and deductibles are required. In some plans, the number of postpartum hospital days may be restricted (1). In addition, some important tests and procedures (e.g., Rho-gam,[41] inpatient well-baby care) may be excluded from coverage (1).

Waiting periods and preexisting condition exclusions may be required in some health plans and are especially significant in maternity care given the critical importance of early prenatal medical attention. Forty-five percent of employees of medium and large firms are not eligible for health benefits until after completing some period of service, usually 3 months or less (84). Consequently, adolescents who become pregnant, before or shortly after a parent's job change, may not be covered for prenatal care, at least during the first trimester of pregnancy.

Waiting periods for preexisting conditions can also limit or even eliminate maternity coverage if conception occurred previous to the effective date of the health policy. The 1984 Bureau of Labor Statistics survey found that almost 60 percent of health plan participants were not covered for preexisting conditions for 10 or more months after health coverage starts (1). It is not clear how many adolescent mothers lose access to maternity coverage as a result.

It is important to note that the newborn infants of privately insured adolescent mothers are especially at risk for being uninsured. In 1987, the Alan Guttmacher Institute surveyed Blue Cross and Blue Shield plans and leading commercial insurers regarding maternity and newborn health coverage (1).[42] The survey's results indicated that almost 70 percent of the health plans did not cover newborns of nonspouse dependents (e.g., adolescent daughters). Thirty percent of the plans covered neither the adolescent mother for her maternity-related care nor her newborn.

Abortion Services—Although there are no data describing private health coverage of abortion, it appears that some health plans may exclude it. At least eight States (i.e., Idaho, Kentucky, Minnesota, Missouri, Nebraska, North Dakota, Pennsylvania, and Rhode Island) have mandated some restriction of private health insurance benefits for abortions (33). Four States (i.e., Idaho, Kentucky, Missouri, and North Dakota) require that coverage be provided only on an optional basis and at extra cost.[43] Nebraska, Pennsylvania, and Rhode Island prohibit abortion coverage in health plans provided to public employees; however, they allow exceptions when the mother's life is threatened.[44] Pennsylvania and Rhode Island also allow coverage for public employees in cases of rape or incest.[45] Minnesota prohibits a State mandate for HMO abortion coverage unless the mother's life is threatened (33).

The Pregnancy Discrimination Act does not preclude coverage, but it specifically relieves employers of any obligation to provide abortion benefits ''except where the life of the mother would be endangered if the fetus were carried to term, or except where medical complications have arisen from an abortion'' (Public Law 95-555). If abortion coverage is provided, however, ''the employer must do so in the same manner and to the same degree as it covers other medical conditions'' (29 CFR 1985 ed. 1604, App.).

Each year since 1982, the Federal Government has prohibited funding for abortion in the Federal Employee Health Benefits Program except when the life of the mother would be endangered if the fetus were carried to term (Public Law 100-202, Title V, Sec. 517, 1987).

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[41] A *Rho-gam* (Rho immune globulin immunization) is indicated for Rh negative pregnant women to prevent the formation of antibodies against the fetus that can cause a miscarriage or stiilbirth (1).

[42] The Alan Guttmacher Institute survey was conducted in early 1987 and included 100 leading commercial group health insurers and all the Nation's Blue Cross and Blue Shield plans; the response rate was 73 percent (1).

[43] The Pennsylvania regulation requiring an additional premium for abortion coverage was found to be unconstitutional in Federal court [*American College of Obstetricians* v. *Thornberg* 737 F2d 283, 303 [3rd Cir.1984]]. The State continnes, however, to prohibit abortion as a ''basic'' benefit and requires that coverage for induced abortions be offered only on an optional basis.

[44] A 1984 Federal court decision ruled that Rhode Island could not direct municipalities from withholding funds for abortion coverage but the State may (and does) prohibit abortion coverage for State employees.

[45] Rhode Island's regulation mandating that coverage be offered only as an optional benefit and at extra cost was struck down as unconstitutional by a Federal court decision, *National Education Association of Rhode Island et al.* v. *J. Joseph Garrahy et al.* in 1984 (598 F. Supp.1374, 1984).

Contraception—Although health benefit survey data do not provide specific details on family planning coverage, some inferences can be drawn from available information on preventive services and prescription drugs. The typical adolescent family planning visit consists of several components, including a pelvic examination, pap smear, sexually transmitted disease screening, counseling, and possibly a prescription for a birth control drug or device. Since private health plan benefits for routine physical exams and related tests are often not covered, except in an HMO setting, it is less likely that such a visit would be reimbursable unless the claim was associated with a diagnosis (e.g., nonmenstrual bleeding). The laboratory tests would always be covered if they were interpreted by the insurer as "diagnostic" rather than preventive. Prescription drug benefits are available to 93 percent of participants in employee-based health plans. Thus, most privately insured adolescents probably have coverage for birth control pills. Whether birth control devices (e.g., diaphragms) are covered by most health plans is not known.

Dental Care—In 1988, 37 percent of participants in employer-sponsored group health plans had general dental care coverage and 27 percent were covered for orthodontic expenses (32). Most of these plans include benefits for preventive care, such as routine examinations and X-rays, and restorative procedures (e.g., fillings, periodontal care).

Dental benefits are typically provided with separate annual dollar maximums, deductibles, and coinsurance requirements. In 1988, the most common annual maximum benefit was $1,000. Coinsurance requirements often depend on the type of procedure. The less costly procedures (e.g., examinations, X-rays) are usually covered at a higher rate, typically ranging from 80 to 100 percent of the "usual, customary, and reasonable" charge (84). Expensive procedures, including orthodontia, are commonly limited to a 50-percent maximum. Payment for orthodontia is also frequently restricted to a lifetime maximum of no more than $1,000 per child dependent (84).

Long-Term Care for the Chronically Ill or Disabled—In 1987, a survey focusing on private health insurance coverage of chronically ill children younger than 18 years old was conducted for the first time (24).[46] The findings are summarized below.

Ancillary Services, Equipment, and Supplies—The researchers concluded that the basic therapeutic needs of chronically ill children are not always met by employment-based health plans (24). Physical therapy, speech therapy, and occupational therapy were covered by 89 percent, 77 percent, and 57 percent, respectively, of the surveyed health plans. In some benefit plans, these therapies were only available for short-term rehabilitation purposes. However, many ancillary medical services, such as diagnostic X-ray and laboratory services, medical supplies and medical equipment, and outpatient prescription drugs were covered by more than 90 percent of the surveyed health plans. Benefits for nutritionists' services were rarely available and coverage was restricted to physician prescriptions for purposes other than weight loss or control.

Long-Term Care—Traditional benefits for long-term care, such as institutional care, visiting nurse, and home health aide services are usually rather limited if available at all (24). Most of the health plans surveyed restrict the number of in-home nurse and home health aide services; only one-third provided for a limited stay in a skilled nursing home facility. Yet health insurance coverage of high-cost illnesses and conditions that require long-term attention is evolving. Many insurers and employers have introduced more comprehensive coverage that includes skilled nursing, home health aides, physical therapy, respiratory therapy, and benefits for medical social work, in order to contain the more expensive costs of institutionalization. Sixty-nine percent of the surveyed health plans took this approach, although the number of covered visits for most of the plans was limited to 90 visits per year. Home care benefits are often provided as a substitute for hospitalization and are usually not reimbursable unless they help reduce or avoid a stay in a more costly institution. Sometimes home care benefits are provided only in order to cut short an ongoing hospital stay.

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[46] This survey included 150 employers including 50 small (0 to 100 employees), 46 medium (101 to 500 employees), and 54 large (more than 500 employees) firms chosen at random from the Dun and Bradstreet *U.S. Business Directory* and the *Business Insurance Directory* (24).

Some health plans reflect a new flexibility in the coverage of costly chronic conditions and now include provisions for "individual benefits management" (24). These new health plan provisions allow for payment of otherwise *uncovered* home- and community-based services as long as the total cost of providing care is less than the cost of more expensive *covered* services. Half of the surveyed health plans either had such a program or allowed it on a case-by-case basis when requested by a physician or family member even if the provided services were not explicitly covered.

Nonphysician Providers and Alternative Settings—Private health insurance coverage is principally oriented towards payment for physicians and physician-supervised or physician-ordered services. Data describing coverage of nonphysician providers is sketchy at best. How nurse practitioners, psychologists, clinical social workers, drug addiction counselors, and other nonphysician health care providers are paid for their services can be key to developing additional low-cost community adolescent health resources. While many States allow these providers an expanded scope of practice, they may face obstacles in getting direct reimbursement for their services whether they practice in a traditional health care setting or elsewhere. Although many States mandate private health insurance coverage of some nonphysician providers, especially psychologists, social workers, nurse practitioners, and clinical nurse midwives, it is not clear how many health insurance plans allow for direct payment for their services since a substantial percentage of employment-based health coverage is free from State insurance regulation (see earlier discussion of the Employee Retirement and Income Security Act).

Medicaid Coverage[47] [48] [49]

An estimated 4.58 million U.S. adolescents ages 10 through 18 had Medicaid coverage at some point in time during fiscal year 1988.[50] Although nearly all adolescents with Medicaid coverage live in families with incomes below the Federal poverty level, poor adolescents are still more likely to be uninsured than others. In fact, in calendar year 1988, one out of three poor adolescents, more than 1.7 million overall, had neither Medicaid nor private health insurance coverage. An additional 932,000 adolescents whose families lived just above the poverty level (i.e., from 100 to 149 percent of the Federal poverty level) were also without coverage.[51]

Instead of being regarded as a single program, the Medicaid program may be more aptly described as a confederation of 50 State programs. Although Federal guidelines determine broad eligibility and coverage criteria, each State designs and manages its own Medicaid program. Consequently, eligibility requirements, services offered, utilization limits, and provider payment policies vary widely among the States. How well Medicaid covers poor adolescents depends to a large extent on these State-specific features and, thus, they are the focus of this review. The State-specific information reported here, unless noted otherwise, is based on a 1989 survey of State Medicaid benefits and eligibility policies, conducted by Fox Health Policy Consultants and McManus Health Policy, Inc. (48).[52]

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[47] For a more in-depth discussion and review of the complex regulations governing Medicaid eligibility and coverage, see the *Medicaid Source Book: Background Data and Analysis* (69).

[48] Every State but Arizona participates in the Medicaid program. Arizona provides federally funded medical assistance through a demonstration program that has received waivers of certain Medicaid requirements. The Arizona Medicaid program is not included in this review.

[49] The District of Columbia is included in any data summarizing State Medicaid programs.

[50] This estimate was developed for OTA by the Office of the Actuary, Health Care Financing Administration (HCFA), U.S. Department of Health and Human Services, and includes all individuals ever-enrolled in fiscal year 1988. HCFA estimates that children in the AFDC program are enrolled for an average of 9 months during a fiscal year (see app. C in this volume for details on HCFA's method of estimation). In contrast, data from the March 1989 Current Population Survey, a household-based survey of noninstitutionalized persons, found that 2.96 million adolescents had Medicaid coverage only in calendar year 1988. An additional 23 to 25 percent had both Medicaid and private coverage in 1988 according to the Current Population Survey.

[51] This number is based on estimates from the U.S. Census Bureau's March 1989 Current Population Survey developed by Richard Kronick for OTA (45).

[52] This Medicaid survey was supported by a grant (# MCH-063500) from the Bureau of Maternal and Child Health and Resources Development, and the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services. The survey was conducted by telephone in the spring of 1989 and focused on selected mandatory and optional Medicaid services critical to adolescents. An attempt was made to interview each State's director of Medicaid coverage policy. If that person was unavailable, a deputy or other responsible individual was contacted. Draft summary tables of the survey findings were returned to the State Medicaid director for their review and comment.

Table 16-7—Estimated Medicaid Enrollment and Expenditures, by Age Group, Fiscal Year 1988

Age group	Estimated number of enrollees[a] (in millions)	Average cost per enrollee[b]	Estimated expenditures (in millions)	Percent of total program costs[c]
0-5[d]	6.048	$ 669	$ 4,046	8.4%
6-14	5.417	445	2,411	5.0
10-18	4.583	725	3,322	6.9
15-20	2.737	1,109	3,035	6.3
21-24	6.642	1,939	12,879	26.6
45-64	2.079	3,627	7,541	15.6
65 and over	3.779	4,899	18,513	38.2
All ages	26.702	$1,814	$48,425	100.0%

[a] Numbers of individuals ever enrolled in fiscal year 1988.

[b] Costs per enrollee were calculated based on the number of individuals ever enrolled in Medicaid in fiscal year 1988.

[c] Percentages may not total 100 due to rounding.

[d] In some States, expenditures for newborn infants may be assigned to the mother.

SOURCE: Office of Technology Assessment, 1991, based on unpublished HCFA-2082 data on Medicaid enrollment and expenditures in fiscal year 1988 from the Office of the Actuary, Health Care Financing Administration, U.S. Department of Health and Human Services, Baltimore, MD, June 1990.

Throughout this review, it is critical that the reader keep in mind that what is described are State policies, *not* actual availability of services. It is well established that despite the features of Medicaid that have enabled *some* poor children and adolescents to gain access to health care, this access is often constrained by both Federal and State Medicaid policies and requirements.

Who Pays for Medicaid?

Medicaid is a joint Federal-State entitlement program and its costs are shared by Federal and State governments. The Federal share in each State's Medicaid program ranges from 50 to 80 percent and in fiscal year 1990 total expenditures were projected to total approximately $70.5 billion (71). Federal funds account for 56.9 percent of total Medicaid program expenditures, an estimated $40.2 billion in fiscal year 1990 (71).

Medicaid Expenditures on Adolescents[53]

Actual data on Medicaid expenditures for adolescents are not available. Using vendor payment data from a sample of 35 States, however, the Health Care Financing Administration (HCFA) has estimated that fiscal year 1988 national Medicaid expenditures for adolescents ages 10 to 18 totaled approximately $3.322 billion; about 44 percent of this was spent on 10- to 14-year-olds and 56 percent on 15- to 18-year-olds (81). Overall, adolescents ages 10 to 18 made up 17.1 percent of Medicaid enrollment and 6.9 percent of overall Medicaid expenditures in fiscal year 1988 (see table 16-7).

Table 16-8 shows the allocation of fiscal year 1988 Medicaid expenditures by type of service. Hospital inpatient, physician services, and intermediate care facilities for the mentally retarded (ICF/MR) accounted for more than half of all Medicaid expenses incurred for adolescents. Although the distribution of costs for younger adolescents (10- to 14-year-olds) v. older adolescents (15- to 18-year-olds) was similar, per enrollee expenditures were almost three-quarters higher for older adolescents than for the younger group. Per enrollee costs for family planning, hospital inpatient, ICF/MR, home health care, inpatient mental health, and physician services were substantially higher for 15- to 18-year-olds than for younger adolescents.

Which Adolescents Are Eligible for Medicaid?

One reason that so many poor adolescents are not covered by Medicaid is that eligibility has generally been linked to participation in the AFDC cash welfare program (69). AFDC eligibility hinges not

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[53] These estimates were developed by the Office of the Actuary, Health Care Financing Administration (HCFA), U.S. Department of Health and Human Services and were based on fiscal year 1988 HCFA-2082 (vendor payment) data for Alabama, Alaska, Arkansas, Colorado, District of Columbia, Florida, Georgia, Idaho, Illinois, Iowa, Kansas, Louisiana, Maine, Maryland, Massachusetts, Mississippi, Montana, Maine, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, and West Virginia (81). Enrollee data include all institutionalized and noninstitutionalized individuals ever enrolled in Medicaid during fiscal year 1988. For further details regarding HCFA's method of estimating Medicaid enrollees and expenditures, see app. C in this volume.

Table 16-8—Estimated Medicaid Expenditures on Adolescents Ages 10 to 14 and 15 to 18, by Type of Service, Fiscal Year 1988

Type of service	Estimated expenditures (in millions)			Percentage of total costs[a]			Estimated costs per enrollee[b]	
	10-14	15-18	10-18	10-14	15-18	10-18	10-14	15-18
Hospital (general)[c]	$ 421	$ 667	$1,088	28.7%	36.0%	32.8%	$159	$346
Hospital (mental health)	155	193	348	10.6	10.4	10.5	58	100
Intermediate care facility for the mentally retarded (ICF/MR)	145	252	397	9.9	13.6	12.0	55	131
Intermediate care facility/other	7	4	11	0.5	0.2	0.3	3	2
Skilled nursing facility	29	30	59	2.0	1.6	1.8	11	15
Physician services	172	210	382	11.7	11.3	11.5	65	109
Dental services	73	55	128	5.0	3.0	3.9	28	28
Other practitioners	25	19	44	1.7	1.0	1.3	10	10
Hospital outpatient	154	153	307	10.5	8.3	9.2	58	79
Clinic services	63	53	116	4.3	2.9	3.5	24	28
Home health care	17	20	37	1.2	1.1	1.1	6	11
Family planning	3	13	16	0.2	0.7	0.5	1	7
Lab/radiology	28	36	64	1.9	1.9	1.9	11	18
Prescription drugs	76	66	142	5.2	3.6	4.3	29	34
EPSDT[d]	10	5	15	0.7	0.3	0.5	4	3
Rural health clinics	1	1	2	—[e]	—[e]	—[e]	1	1
Other care	89	76	165	6.1	4.1	5.0	33	40
Total	$1,468	$1,854	$3,322	100.0%	100.0%	100.0%	$552	$963

[a] Percentages may not total 100 because of rounding.

[b] Costs per enrollee were calculated using the following estimates of individuals ever enrolled in fiscal year 1988: 2.657 million 10- to 14-year-olds and 1.926 million 15- to 18-year-olds.

[c] This includes mental health stays in psychiatric units of general, acute care hospitals if the unit is not administratively separate for billing purposes.

[d] Early and Periodic Screening, Diagnosis, and Treatment program benefit screening costs only.

[e] Less than 0.5 percent.

SOURCE: Office of Technolgy Assessment, 1991, based on estimates from unpublished HCFA-2082 data on Medicaid enrollment and expenditures in fiscal year 1988 from the Office of the Actuary, Health Care Financing Administration, U.S. Department of Health and Human Services, Baltimore, MD, June 1990.

only on whether family income and resources fall within the State's AFDC limits but also, with few exceptions, on whether the family has a so-called "deprivation factor" (i.e., at least one parent is dead, disabled, continually absent from the home, or, as of October 1990, in two-parent families whose principal breadwinner is unemployed).[54]

States have the option, under Federal law, to offer Medicaid to "medically needy" children and adolescents when their family income and resources lie above the AFDC need standards *if* they meet AFDC's categorical requirements (e.g., an absent parent or disability). Thirty-seven States currently operate medically needy programs (53). Each State has the right to set its own medically needy eligibility standards, provided they do not exceed 133.33 percent of the maximum AFDC assistance thresholds for similarly sized families (see table 16-9). Through a spend-down provision, individuals with incomes above the medically needy standard also may become eligible if their medical expenses are high enough to reduce their countable income below the medically needy maximum. Those who enter the program by "spending down" typically have erratic access to Medicaid and may only be eligible for a single accounting period (e.g., 6 months). If a State has a medically needy program, it must provide participants all mandatory Medicaid benefits and may elect to offer the same optional benefits package available to the categorically needy in the State.[55] Most of the 37 States with medically

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[54] The Family Support Act of 1988 (Public Law 100-485) requires that, starting Oct. 1, 1990, all States provide AFDC and Medicaid coverage to families whose principal wage-earner is unemployed if they meet AFDC income and resource requirements. Coverage is limited, however, to 6 months out of any 12-month period.

[55] "Categorically needy" refers to those who are Medicaid-eligible by belonging to certain categories of poor people, such as those who are a member of a family with dependent children where one parent is absent, incapacitated, or (in some States) unemployed.

Table 16-9—Annualized Income Thresholds for Medicaid Eligibility,[a] by State, January 1990

States	AFDC threshold for a family of 3	Percent of poverty level ($10,580[b])	Medically needy threshold for a family of 3[c]	Percent of poverty level ($10,580[b])
Alabama	$ 1,416	13.4%	NA	NA
Alaska	10,152	76.9	NA	NA
Arizona	3,516	33.3	NA	NA
Arkansas	2,448	23.2	$ 3,300	31.3%
California	8,328	78.9	11,208	106.1
Colorado	5,052	47.8	NA	NA
Connecticut	6,660	63.1	8,856	83.9
Delaware	3,996	37.8	NA	NA
District of Columbia	4,908	46.5	6,540	61.9
Florida	3,528	33.4	4,800	45.5
Georgia	4,968	47.0	4,404	41.7
Hawaii	7,224	59.5	7,224	59.5
Idaho	3,780	35.8	NA	NA
Illinois	4,404	41.7	5,904	55.9
Indiana	3,456	32.7	NA	NA
Iowa	4,920	46.6	6,600	62.5
Kansas	4,596	43.5	5,580	52.8
Kentucky	6,312	59.8	3,696	35.0
Louisiana	2,280	21.6	3,096	29.3
Maine	7,824	74.1	7,296	69.1
Maryland	4,752	45.0	5,508	52.2
Massachusetts	6,468	61.3	9,300	88.1
Michigan	6,900	65.3	6,660	83.1
Minnesota	6,384	60.5	8,508	80.6
Mississippi	4,416	41.8	NA	NA
Missouri	3,468	32.8	NA	NA
Montana	4,308	40.8	4,920	46.6
Nebraska	4,368	41.4	5,904	55.9
Nevada	3,960	37.5	NA	NA
New Hampshire	7,116	67.4	6,072	57.5
New Jersey	5,088	48.2	6,792	64.3
New Mexico	3,168	30.0	NA	NA
New York	7,476	70.8	8,508	80.6
North Carolina	3,324	31.5	4,404	41.7
North Dakota	4,632	43.9	5,220	49.4
Ohio	3,852	36.5	NA	NA
Oklahoma	5,652	53.5	5,196	49.2
Oregon	5,184	49.1	6,900	65.3
Pennsylvania	5,052	47.8	5,604	53.1
Rhode Island	6,516	61.7	8,700	82.4
South Carolina	5,028	47.6	3,300	31.3
South Dakota	4,524	42.8	NA	NA
Tennessee	4,644	44.0	3,000	28.4
Texas	2,208	20.9	3,204	30.3
Utah	6,192	58.6	6,192	58.6
Vermont	7,944	75.2	10,596	100.3
Virginia	3,492	33.1	4,296	40.7
Washington	6,012	56.9	7,188	68.1
West Virginia	2,988	28.3	3,480	33.0
Wisconsin	6,204	58.8	8,268	78.3
Wyoming	4,320	40.9	NA	NA
Average State	$ 5,008	46.9%	$ 6,114	57.7%

NA = not applicable; the State does not cover the medically needy under its Medicaid program.

[a] The term "threshold" refers to that income limit that truly drives program eligibility. In most States, this is the payment standard. In Colorado, Georgia, Kentucky, Maine, Michigan, Mississippi, Oklahoma, South Carolina, Tennessee, and Utah, the threshold is the State's need standard. Please note, in these 10 States, the threshold that appears on the table is not what the State pays to AFDC recipients. These States' payment standards are actually significantly lower than the eligibility threshold.

[b] The Federal poverty level for a family of three is $10,580 in all States but Alaska and Hawaii where the levels are higher: Alaska family of three = $13,200; Hawaii family of three = $12,150.

[c] The "medically needy" are not covered in Alabama, Alaska, Arizona, Colorado, Delaware, Idaho, Indiana, Mississippi, Missouri, Nevada, New Mexico, Ohio, South Dakota, and Wyoming.

SOURCE: National Governors' Association, "MCH Update—State Coverage of Pregnant Women and Children," Washington, DC, January 1990.

needy programs provide participants the full range of Medicaid benefits offered in their State (80).[56]

Eligibility for Medicaid among poor adolescents varies a great deal among the States because income and resource standards for the AFDC and medically needy programs are determined by the individual States. In many States, the standards underlying eligibility are quite stringent. In the South, as noted earlier in the discussion on uninsured adolescents, it appears that more stringent income eligibility requirements are key to that region's greater proportion of uninsured adolescents.[57]

As of January 1990, very few State AFDC and medically needy income standards approached Federal poverty levels and many fell short of 50 percent of the Federal poverty guideline of $10,560 for a family of three (see table 16-9).[58] Annual AFDC Medicaid eligibility thresholds for a family of three range from a low of $1,416 in Alabama to a high of $8,328 in California (53).[59] In many cases, the States have failed to adjust the AFDC income standards for inflation and, consequently, the income threshold as a percentage of poverty has been eroded substantially, from an average of 71 percent in 1975 to 47 percent in January 1990 (51). Whether all States would be able to bear the burden of improving eligibility requirements, without further Federal assistance, is unclear.

The Medicaid link with AFDC participation is the primary, but not the only, way to establish Medicaid eligibility. Under Federal law, in addition to providing mandatory Medicaid coverage of AFDC recipients, States may also choose to cover children who meet the AFDC program's income and resource requirements but are without a "deprivation factor"—e.g., adolescents who live in a financially needy two-parent family.[60] Thirty-four States have implemented this option.[61] [62] The Family Support Act of 1988 (Public Law 100-485) requires that, starting October 1, 1990, all States must provide AFDC coverage to families whose principal wage earner is unemployed if they meet the income and resource requirements of AFDC eligibility.

Congress has acted in recent years to sever the eligibility link between Medicaid and AFDC for pregnant women and young children. But with the exception of some pregnant adolescents, today's generation of poor adolescents have not benefited from these reforms. The most recent Medicaid eligibility reform occurred in the Omnibus Budget Reconciliation Act of 1990 (OBRA-90) (Public Law 101-508) and required States to provide Medicaid coverage to all children ages 6 to 19, born *after* September 30, 1983, with family incomes up to 100 percent of the Federal poverty level. In the previous year, the Omnibus Budget Reconciliation Act of 1989 (OBRA-89) (Public Law 101-239) required that as of April 1, 1990, States provide Medicaid benefits to all pregnant women and children up to age 6 with family incomes up to 133 percent of the Federal poverty level. (See box 16-B for a summary of OBRA-89 and OBRA-90's Medicaid provisions affecting adolescents.) Earlier legislation gave States the *option* to extend Medicaid eligibility up to 185 percent of poverty for pregnant women, and 15 States have done this;[63] and another 4 States have

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[56] Twenty-two States provide the full range: California, Connecticut, District of Columbia, Georgia, Hawaii, Illinois, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nebraska, New Hampshire, New York, North Carolina, North Dakota, Texas, Vermont, and West Virginia (80).

[57] The U.S. Bureau of the Census defines Southern States as Alabama, Arkansas, Delaware, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia (77).

[58] In order to be eligible for AFDC payments and automatically eligible for Medicaid, a family must pass two income tests: a gross income test and a "countable" income test. Gross monthly income cannot exceed 185 percent of the State's need standard. Countable income must be less than the State's need standard allowing for child care costs up to $160 per child and a standard allowance of $75 per month. AFDC recipients are allowed an additional "income disregard" as an incentive to return to or enter the workforce (69).

[59] The eligibility threshold in Alaska is even higher (i.e., $10,152), but this is not comparable to the thresholds in the contiguous 48 States. The Federal Government has established separate poverty levels for both Alaska and Hawaii because of their unique economic conditions.

[60] Often referred to as "Ribicoff children" after former Senator Ribicoff, the sponsor of legislation authorizing coverage for this group.

[61] The 34 States are Alaska, Arkansas, California, Connecticut, District of Columbia, Florida, Georgia, Hawaii, Illinois, Iowa, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia, and Wisconsin.

[62] States may choose to extend categorically needy coverage to other groups of AFDC-related persons; for greater detail see the *Medicaid Source Book: Background Data and Analysis* (69).

[63] The 15 States are California, Connecticut, Hawaii, Iowa, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, New York, Rhode Island, South Carolina, Vermont, and Washington.

Box 16-B—Provisions of the Omnibus Budget Reconciliation Acts of 1989 and 1990 That Affect Medicaid Coverage of Adolescents[1]

Medicaid Eligibility

- States must extend Medicaid eligibility to all pregnant women and children and to children up to age 6 with family incomes up to 133 percent of the Federal poverty level (i.e., the poverty level is $10,560 for a family of three). (OBRA-89)
- States must extend Medicaid eligibility to all children ages 6 to 19, who were born after September 30, 1983, and whose family incomes are up to 100 percent of the Federal poverty level.[2] (OBRA-90)

Medicaid Coverage

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) (OBRA-89)

- Any State Medicaid coverage limitations on diagnosis or treatment are eliminated for health conditions identified during the course of an EPSDT screen as long as the services are within the limits of Federal Medicaid guidelines and are deemed medically necessary.
- States are required to provide periodic screens at intervals which meet reasonable standards of medical and dental practice as determined by the State after consultation with recognized medical and dental organizations. Unscheduled screenings must be permitted if medically necessary.
- Screening services must include health education and anticipatory guidance.
- Vision, hearing, and dental services must be provided, each according to its own periodicity schedule that meets reasonable practice standards.

Pediatric and Family Nurse Practitioners (OBRA-89)

- State Medicaid programs must cover certified pediatric and family nurse practitioners to the extent that they are legally authorized by State law to provide services, even if they are not practicing under the supervision of, or associated with, a physician or other provider.[3]

Physician Payment (OBRA-89)

- States must submit annual plans specifying Medicaid payment rates for obstetrical and pediatric services for the Secretary's review, and in 1992 average Medicaid payments for specific obstetric and pediatric procedures must be reported.
- The Physician Payment Review Commission must examine the adequacy of physician payment, physician participation, and access to care by Medicaid beneficiaries and report to Congress by July 1, 1991.

Medicaid and Private Insurance (OBRA-89)

- Requires States to pay group health insurance premiums with Medicaid funds, if cost effective, for individuals or families with one Medicaid eligible member (whose incomes are below the Federal poverty level) if they are eligible for such insurance coverage.[4]

Other Provisions

- States must cover the ambulatory services of community health centers, migrant health centers, and health care for the homeless programs receiving funds under sections 329, 330, or 340 of the Public Health Service Act, and must reimburse these services at 100 percent of reasonable cost. Health center services must include physician services, physician assistant and nurse practitioner services (to the extent allowed by State law), clinical psychologist services, and clinical social worker services. (OBRA-89)
- The Secretary is directed to conduct demonstration projects in several States to assess ways of extending Medicaid coverage, or alternative coverage, to pregnant women and children up to age 20 who are otherwise ineligible for Medicaid and whose family incomes are below 185 percent of poverty. Alternative coverage may include, but is not limited to, such options as enrollment under employer plans, the State's plan for its own employees, a State uninsured plan, or an HMO. (OBRA-89)

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[1] All provisions of the Omnibus Budget Reconciliation Act of 1989 (Public Law 101-239) regarding Medicaid eligibility or coverage became effective Apr. 1, 1990, unless noted otherwise.

[2] This provision of the Omnibus Budget Reconciliation Act of 1990 (Public Law 101-508) becomes effective July 1, 1991, and will be phased in over 10 years.

[3] This provision became effective July 1, 1990.

[4] This provision became effective Jan. 1, 1991.

Continued on next page

Box 16-B—Provisions of the Omnibus Budget Reconciliation Acts of 1989 and 1990 That Affect Medicaid Coverage of Adolescents—Continued

- The Secretary is directed to conduct up to four demonstration projects to test innovative methods of providing health insurance to medically uninsurable children under age 19. (OBRA-89)
- The Secretary is directed to conduct 3-year demonstration projects in three or four States to provide Medicaid to families with incomes below 150 percent of poverty who are currently ineligible for Medicaid (OBRA-90). Each project must begin no later than July 1, 1991.

SOURCE: **1989 provisions:** Commerce Clearinghouse, Inc., "Omnibus Budget Reconciliation Act of 1989, Explanation of the Conference Committee Affecting Medicare, Medicaid Program," *Medicare and Medicaid Guide*, vol. 3 (Chicago, IL: Dec. 15, 1989); **1990 provisions:** U.S. Congress, House of Representatives, "Omnibus Budget Reconciliation Act of 1990, Conference Report 101-964" (Washington, DC: U.S. Government Printing Office, 1990).

raised the income eligibility limit to 150 percent of poverty[64] (53).

Federal law also dictates that children and adolescents under age 21 are eligible for Medicaid if they are in foster care under Title IV-E of the Social Security Act. In addition, every State but New Hampshire has extended Medicaid coverage to blind or disabled children and adolescents receiving cash assistance from the Supplemental Security Income (SSI) program. States have the option of limiting coverage of SSI recipients by requiring them to meet more restrictive eligibility standards although 42 States cover all disabled adolescents who receive Federal SSI cash assistance (21).

Although adolescents principally gain access to Medicaid through their parents, some, especially poor pregnant or parenting adolescent females, may establish eligibility on their own. Total numbers are not available; however, among adolescents ages 10 to 18 who received AFDC benefits in fiscal year 1987, approximately 5 percent participated in AFDC (and presumably Medicaid as well) as an "adult" or head of household (78). Overall, more than 110,000 female adolescents and almost 11,000 males were "adult" AFDC recipients that year.

What Medicaid Coverage Provides

As noted earlier, each State defines not only the eligible Medicaid population it serves but also its own Medicaid benefit package (within broad Federal guidelines). All States are required to offer a core group of services, referred to as "mandatory," including but not limited to inpatient and outpatient hospital services, laboratory and radiology services, physician services, clinical nurse midwife services,[65] certified pediatric and family nurse practitioner services, family planning services and supplies,[66] and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services for children and adolescents under age 21 (see table 16-10).

In addition, Federal law permits State Medicaid programs, at their discretion, to provide a range of "optional" services to the categorically needy, including clinic services, dental services, physical therapy, occupational therapy, speech pathology and audiology, rehabilitative services, case management, inpatient psychiatric services for persons under age 21, other licensed practitioner services (such as psychologists), and prescription drugs (see table 16-10).

Although a Medicaid card appears to entitle a poor adolescent to a rather expansive package of health benefits, States can and do establish strict limits on the frequency and number of covered services regardless of whether they are mandatory or optional benefits. In addition, States may impose utilization control measures to ensure that services are medically necessary. Under Medicaid, "a serv-

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[64] The four States are Florida, Kansas, North Carolina, and West Virginia.

[65] Mandatory nurse midwife services are whatever services the nurse midwife is authorized to practice under State law or regulation.

[66] Mandatory family planning services and supplies include services and supplies for women of childbearing age, including sexually active minors who desire such services and supplies. Abortions are excluded from family planning services, and Federal Medicaid matching payments for abortions have been limited, by language in the U.S. Department of Health and Human Services' appropriations bills, to cases where the life of the mother is in danger (69).

Table 16-10—Mandatory and Optional Services Covered Under Medicaid

Mandatory services
- Inpatient hospital services
- Outpatient hospital services
- Physician services
- Early and Periodic Screening, Diagnosis, and Treatment services for children under age 21
- Family planning services and supplies
- Laboratory and X-ray procedures
- Skilled nursing facility and home health care services for adults (i.e., 21 years and older)
- Rural health clinic services
- Services of certified nurse-midwives, pediatric and family nurse practitioners[a]
- Community health centers, migrant health centers, and health care for the homeless programs receiving funds under sections 329, 330, or 340 of the Public Health Service Act

Optional services
- Case management
- Additional home health services
- Dental services
- Services of other licensed practitioners, including psychologists, chiropractors, optometrists, and podiatrists
- Clinic services
- Other diagnostic, screening, preventive, and rehabilitative services
- Prescription drugs
- Intermediate care facility services, including intermediate care facility services for the mentally retarded
- Eyeglasses, prosthetic devices, dentures, and orthopedic shoes
- Home and skilled nursing facility care for children
- Private duty nursing
- Inpatient psychiatric care for children under age 21
- Physical, occupational, and speech, hearing, and language disorder therapies
- Other medical or remedial care recognized under State law, including personal care in the home, transportation, and emergency services, skilled nursing facility for children under age 21, Christian Science nurses and sanitariums, hospice care services, respiratory care service

[a] To the extent they are authorized to practice under State law or regulation.

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, Division of Intergovernmental Affairs, *Medicaid Services State by State*, HCFA Pub No. 02155-90 (Washington, DC: U.S. Govermnent Printing Office, October 1989).

ice is medically necessary if it is reasonably calculated to prevent, diagnose, correct, cure, alleviate, or prevent the worsening of conditions that endanger life, cause suffering or pain, result in illness or infirmity, threaten to cause or aggravate a handicap, or cause physical deformity or malfunction, and if there is no other equally effective (although more conservative or less costly) course of treatment available or suitable for the recipient requesting the service'' (10).

State Medicaid benefits of particular relevance to adolescents—including the EPSDT benefit, physician services, nurse practitioner services, hospital outpatient services, school-based clinics, mental health care services, and substance abuse treatment—are reviewed below.

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Benefit—As part of OBRA-89 (Public Law 101-239), Congress significantly expanded adolescents' and other children's access to Medicaid-covered services by reforming the EPSDT program.[67]

States are mandated by the Federal law to periodically screen[68] Medicaid-eligible adolescents for any illnesses, abnormalities, or treatable conditions and refer them for definitive treatment. Screens must contain certain key components, including the following:

- comprehensive health and developmental history (including assessment of both physical and mental health development),
- comprehensive unclothed physical exam,
- appropriate immunizations according to age and health history,
- laboratory tests, and
- health education (including anticipatory guidance) (42 CFR 441.56(a)).

Vision, hearing, and dental services must be provided as well, each according to its own periodicity schedule that meets reasonable practice standards.

The EPSDT benefit is, in effect, the Nation's largest preventive health program for children and adolescents (68). The OBRA-89 amendments dramatically broadened Medicaid coverage of children and adolescents by essentially eliminating any State Medicaid limitations on diagnosis or treatment for any health condition identified during the course of an EPSDT screen as long as the services are within the limits of Federal Medicaid guidelines and are deemed medically necessary. Services provided under EPSDT must be sufficient in amount, duration, or scope to reasonably achieve their purpose; however, States are permitted to set ''appropriate'' limits on EPSDT services based on medical necessity (79). The act further aims to improve access to

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[67] The EPSDT amendments became effective Apr. 1, 1990.

[68] See details on the periodicity schedule below.

Table 16-11—EPSDT Screening Costs, by Age Group, Fiscal Year 1988

Age group	Estimated number of enrollees (in millions)	Average screening cost per enrollee	Estimated total expenditures (in millions)	
0-5	6.048	$15	$90.7	(72.0%)
6-14	5.417	5	27.1	(21.5%)
10-14	2.657	4	10.6	(8.4%)
15-18	1.926	3	5.8	(4.6%)
15-20	2.737	3	8.2	(6.5%)
Overall (20 and under)	14.202	$9	$126.0	(100%)

SOURCE: Office of Technology Assessment, 1991, based on estimates from unpublished HCFA-2082 data on Medicaid enrollment and expenditures in fiscal year 1988 from the Office of the Actuary, Health Care Financing Administration, U.S. Department of Health and Human Services, Baltimore, MD, June 1990.

EPSDT by expanding the pool of eligible EPSDT providers and permitting more frequent screenings.

Here is an example of the potential of EPSDT to go beyond the limitations of a State's Medicaid program:

> A 14-year-old boy receives an EPSDT health screen and evidence of cocaine use is detected. After intense questioning, the boy admits to regular use of cocaine and his parents agree to have him enter a drug detoxification and counseling program. Under the State plan, the only drug treatment Medicaid will reimburse is heroin detoxification. Medicaid now would be obligated to reimburse for the boy's detoxification and counseling program to the extent it is medically necessary since the need for the treatment was discovered during the EPSDT screen (20).

Clearly, the potential for providing comprehensive health services using EPSDT will not be fully realized, however, if adolescent Medicaid recipients do not get screened. Although the EPSDT program has been shown to improve children's health and reduce health care costs, however, use of EPSDT services by children of all ages is extremely low, especially in rural areas (82). Average program expenditures were only $9 per Medicaid enrollee up to age 20, in fiscal year 1988, and were directed largely towards younger children. HCFA estimates that while, in fiscal year 1988, average per enrollee expenditures for EPSDT screening were $15 per child under age 5, they were only $4 for adolescents ages 10 to 14 and $3 for adolescents ages 15 to 18 (see table 16-11). If all eligible children were screened by the EPSDT program, the costs would be higher. Overall, approximately 72 percent of HCFA expenditures for EPSDT screening have been for 0- to 5-year-olds. In addition, although EPSDT was intended to encompass mental as well as physical assessment, it has tended to be more concerned with the identification and treatment of physical problems (19).

The broad sweep of the OBRA-89 reforms led one policy analyst to conclude that ''the potential of this legislation both to improve the health status of poor adolescents and to stretch the limits of State Medicaid programs is great'' (54). However, the statute comes ''at a time when the Federal Government is requiring States to shoulder more and more of the burden of health care financing'' (54). There is reason to be concerned about the States' capacities to assume these new responsibilities. Medicaid programs now consume an average 14 percent of States' budgets, up from 9 percent in 1980 (43).

EPSDT Screening Schedules—OBRA-89 codifies the periodic nature of EPSDT services and requires that screens be provided at intervals which meet reasonable standards of medical and dental practice as determined by the State after consultation with recognized medical and dental organizations (79). It also requires that any medically necessary interperiodic screening service be covered. But little is known about what health screening periodicity is most appropriate and effective for poor adolescents, especially those at high risk for the common morbidities of adolescence.

The American Academy of Pediatrics recommends that, from ages 10 to 18, adolescents should be screened five times (2). The U.S. Preventive Services Task Force concluded that, from the ages of 7 to 18, except for routine pap smears for sexually active girls from ages 13 to 18, and a tetanus-diphtheria booster between 14 and 16 years, the scheduling of additional visits and the frequency of individual preventive services should be left to

Table 16-12—EPSDT Periodicity Schedules in State Medicaid Programs

State	Number of EPSDT scheduled screenings for ages 10 to 21	State	Number of EPSDT scheduled screenings for ages 10 to 21
States that offer fewer than five scheduled EPSDT screens:		**States that offer five or more scheduled EPSDT screens:**	
Alaska	4	Alabama	6
Arkansas	3	Delaware	6
California	3	Florida	6
Colorado	4	Georgia	6
Connecticut	4	Hawaii	6
District of Columbia	3	Illinois	6
Idaho	1	Indiana	6
Iowa	3	Maine	6
Kansas	4	Maryland	11
Kentucky	4	Massachusetts	6
Louisiana	4	Michigan	6
Mississippi	3	Nebraska	5
Missouri	4	New York	6
Montana	3	North Dakota	11
Nevada	3	Ohio	11
New Hampshire	3	Oregon	6
New Jersey	3	Pennsylvania	6
New Mexico	3	Rhode Island	6
North Carolina	4	Vermont	6
Oklahoma	2	Washington	10
South Carolina	3	West Virginia	7
South Dakota	3	Wisconsin	6
Tennessee	3	**States that schedule as many EPSDT screens as medically necessary:**	
Texas	2		
Utah	3	Minnesota	NA
Virginia	3		
Wyoming	3		

NA = not applicable.

SOURCE: P. McManus, H. Fox, P. Newacheck, et al., unpublished data from a 1989 survey of State Medicaid programs, supported by a grant (#MCH-063500) from the Bureau of Maternal and Child Health and Resources Development, and the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services, Rockville, MD, 1989.

clinical discretion because of lack of data and differing patient risk profiles (85).[69]

In 1989, State EPSDT periodicity schedules varied widely. Twenty-two States covered five or more EPSDT visits for adolescents and young adults ages 10 to 21 (see table 16-12). Maryland, North Dakota, Ohio, and Washington State covered annual EPSDT visits compared with only minimal allowances for one or two preventive visits from ages 10 to 21 in Idaho, Oklahoma, Texas, and Wyoming. Minnesota covers as many EPSDT visits "as medically necessary."

Partial EPSDT Screening—OBRA-89 also clarifies that States may not restrict "partial screeners." This means that the use of all types of providers is now encouraged and those who are qualified to furnish only one EPSDT service cannot be prevented from participating in the program (79). In the past, many States accepted only those providers able to perform "complete" EPSDT screens. Here is an illustration of how this provision might make EPSDT screening services more available to adolescents:

> A teenage girl visits a Planned Parenthood clinic for information on birth control methods. She has no regular primary care physician. Although the clinic does not provide vision or hearing services, it has been certified as an EPSDT screening provider for the purposes of furnishing the comprehensive health and developmental screening component. As a result, the girl is able to obtain a partial EPSDT screening service at the same time she receives family planning services (20).

It is important to note that because of the recent expansions in the EPSDT program, State Medicaid

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[69] Issues regarding the cost-effectiveness of particular periodicity schedules for younger children were addressed in depth in a 1988 OTA study, *Healthy Children: Investing in the Future* (73).

program limits on the physician and other services described below only apply to conditions that are not discovered by EPSDT screening services.

Physician Services—Although all State Medicaid programs are required by Federal law to cover physician services, many States restrict visits to physicians. States may place limits on settings where Medicaid recipients' care can be provided, on the number of visits, and the types of physician services to be covered. Table 16-13 displays each State Medicaid program's coverage of and restrictions on physician services.[70] In 1989, nine States imposed some ceiling on the annual number of office visits to physicians, ranging from 12 to 24 visits per year. Six States did not permit more than one or two physician visits per day; two others set monthly visit limits. Five States require prior authorization for additional physician care after a specified number of visits.

Services of Nurse Practitioners and Other Nonphysician Providers—Whether a State Medicaid program covers nonphysician providers can be key to the development of community resources for adolescent health care. Many school-linked and community-based health centers are staffed principally by nurse practitioners and other nonphysician providers.[71] Under OBRA-89, starting July 1, 1990, State Medicaid programs must cover certified pediatric and family nurse practitioners to the extent that they are legally authorized by State law to provide services, even if they are not practicing under the supervision of, or associated with, a physician or other provider. Thirty-one States currently recognize nurse practitioners in statute or regulation and grant them an expanded scope of practice beyond that of registered nurses (20), but nurse practitioners' legal scope of practice, and the extent of physician supervision they must receive, vary from State to State. Since HCFA regulations are not yet available and only seven States (Florida, Idaho, Kansas, Montana, New Hampshire, Nevada, and Washington) covered nurse practitioners previous to OBRA-89, it is not clear what Medicaid restrictions will be placed on their services.

Forty-five States allow services provided by physician-supervised office staff (e.g., registered nurses) to be reimbursed as a physician service. So, for example, an adolescent's visit for a routine allergy shot given by a physician's nurse can be covered under Medicaid as a physician office visit. Seventeen States exclude physician-supervised speech and other ancillary therapists from the Medicaid program (see table 16-13).

States use a variety of other regulations to govern Medicaid coverage of physician-supervised health providers. Almost half of the 49 States that covered physician-supervised services in 1989 required that the physician be on the premises. Six States required that the physician have direct contact with the patient. Other States used different definitions of physician supervision.

Clinic Services, Including Those of School-Linked Health Centers[72]—Although States are not required by Federal law to cover clinic services under Medicaid, all but three do (Mississippi, Rhode Island, and Wisconsin). States may limit the types of clinics whose services they cover and may include or exclude school-linked health centers, community mental health centers, and substance abuse clinics, among others.[73]

In 1989, only two States—Connecticut and Illinois—permitted school-linked health centers to be authorized Medicaid clinic providers. Even though they are not specifically cited as qualified clinics in a State Medicaid plan, however, school-linked health centers in the other 48 States may receive Medicaid reimbursement. Some of them may receive Medicaid reimbursement because they have been set up as a satellite to an outpatient hospital department or other type of clinic (e.g., rural health clinic or a community health center). School-linked health centers may also receive Medicaid reimbursement through physicians or other qualified providers,

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[70] Note that services provided by psychiatrists are subject to separate limitations in 13 States; see discussion of coverage for mental health and substance abuse treatment below.

[71] For a discussion of school-linked health centers, see ch. 15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Care Services to Adolescents," in this volume.

[72] *Clinic services* are defined under Medicaid to include preventive, diagnostic, therapeutic, rehabilitative, or palliative items or services that are provided to outpatients under direction of a physician or dentist without regard to whether the clinic itself is administered by a physician (69). Clinics providing covered services may provide general health care services or may focus on specific services, for example, mental health services (69).

[73] See ch. 15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents," in this volume for more details on the financing of school-linked health centers.

Table 16-13—Coverage of and Restrictions on Physicians' and Physician-Supervised Services in State Medicaid Programs, 1989

State	Limits on office visits[a]	Prohibited settings	Physician-supervised care: Office nurses[a]	Physician-supervised care: Other practitioners (e.g., physician assistants, ancillary therapists)[a] [b]
Alabama	12 visits/year	—	Yes	No
Alaska	—	—	Yes	Yes
Arkansas	12 visits/year[c]	School, day care	Yes	No
California	—	—	Yes	Yes[d]
Colorado	—	—	Yes	Yes
Connecticut	—	—	Yes	No
Delaware	—	—	Yes	Yes[d]
District of Columbia	—	School, day care, and other	Yes	No
Florida	—	School, day care, and other	Yes	No
Georgia	—[e]	—	Yes	No
Hawaii	—	—	Yes	No
Idaho	—	—	Yes	Yes
Illinois	—	—	Yes	Yes
Indiana	—[e]	—	Yes	No
Iowa	—	—	Yes	No
Kansas	12 visits/year	—	Yes	Yes
Kentucky	—	—	Yes	Yes
Louisiana	12 visits/year	—	Yes	Yes[d]
Maine	—[e]	—	Yes	Yes[d]
Maryland	1 visit/day	—	Yes	Yes[d]
Massachusetts	1 visit/day	—	No	No
Michigan	—	—	Yes	Yes[d]
Minnesota	—	—	Yes	Yes
Mississippi	12 visits/year	—	Yes	Yes[d]
Missouri	—	—	Yes	Yes
Montana	—	—	Yes	No
Nebraska	—	—	Yes	Yes[d]
Nevada	—[e]	—	No	Yes[d]
New Hampshire	18 visits/year	—	Yes	Yes
New Jersey	—	—	Yes	No
New Mexico	—	—	Yes	Yes
New York	—	—	Yes	Yes[d]
North Carolina	24 visits/year[f]	—	No	Yes
North Dakota	—	—	Yes	Yes[d]
Ohio	10 visits/month	—	Yes	Yes
Oklahoma	4 visits/month	—	Yes	No
Oregon	2 visits/day	—	Yes	No
Pennsylvania	—	—	No	Yes[d]
Rhode Island	—	—	Yes	No
South Carolina	18 visits/year	—	No	Yes
South Dakota	—	—	Yes	Yes
Tennessee	24 visits/year	—	Yes	Yes[d]
Texas	—	—	Yes	Yes
Utah	1 visit/day	School	Yes	Yes[d]
Vermont	—[e]	—	Yes	No
Virginia	—	—	Yes	Yes[d]
Washington	1 visit/day	—	Yes	Yes[d]
West Virginia	1 visit/day	—	Yes	No
Wisconsin	—	School, day care	Yes	Yes
Wyoming	—	—	Yes	Yes

KEY: — = None; Yes = covered; No = not covered.

[a] EPSDT visits are not subject to limits.

[b] OBRA-89 mandated State Medicaid coverage of certified pediatric and family nurse practitioners starting July 1, 1990.

[c] For all physician and hospital outpatient services.

[d] Only some licensed practitioners covered under physician supervision.

[e] Prior authorization is required after a certain number of visits have been made.

[f] For all physician, hospital outpatient, and clinic services.

SOURCE: P. McManus, H. Fox, P. Newacheck, et al., unpublished data from a 1989 survey of State Medicaid programs, supported by a grant (#MCH-063500) from the Bureau of Maternal and Child Health and Resources Development, and the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services, Rockville, MD, 1989.

including nurse practitioners, that practice at the clinic, as long as the State does not restrict billing in a school setting. Five States (Arkansas, District of Columbia, Florida, Utah, and Wisconsin) prohibit Medicaid reimbursement for physician services provided in school settings (see table 16-13).

It is not clear to what extent school-linked health centers have established the billing systems necessary to collect Medicaid reimbursement. Numerous administrative obstacles have been cited by some school-linked health centers trying to bill Medicaid for their services, including: difficulty in establishing eligibility of students and obtaining their Medicaid numbers; problems in obtaining provider certification; delays in the reimbursement process and low reimbursement rates; and problems maintaining patient confidentiality (16).

Hospital Outpatient Services—State Medicaid programs are required to cover preventive, diagnostic, therapeutic, rehabilitative, or palliative services provided in a hospital outpatient setting by or under the direction of a physician or dentist. In 1989, seven States imposed some limit on the annual number of hospital outpatient visits, ranging from 3 to 30 visits per year (see table 16-14). Florida set a $1,000 ceiling on outpatients and Oklahoma and the District of Columbia restricted daily outpatient visits to one and two per day, respectively. More than half (i.e., 27) of the States require prior authorization for some hospital outpatient services and 13 States impose ceilings on mental health or ancillary services, such as physical, occupational, and speech therapies.

Mental Health Care[74]—States have considerable flexibility in establishing the nature and extent of mental health services available to Medicaid recipients (66). As in private health insurance coverage, mental health care provided under Medicaid is often constrained by separate and more stringent limits on cost and utilization. The incentives in private mental health benefits to hospitalize patients rather than use nonhospital settings for care also appear to exist in Medicaid. Some argue that Medicaid payment policies appear to discourage less costly treatment alternatives because Medicaid reimbursement rates come closer to covering costs for inpatient care than for outpatient services (63).

Inpatient Mental Health Care—Mental health stays in general hospitals are covered by Medicaid programs in all the States (69). Coverage of inpatient stays in freestanding psychiatric facilities is available for children and adolescents under age 21 in 38 States (almost three out of four) (80),[75] but only 10 of these 38 States permit residential treatment centers and other special psychiatric facilities that are not specifically certified as psychiatric facilities by the Joint Commission on Accreditation of Healthcare Organizations to be reimbursed under Medicaid. Inpatient mental health treatment, regardless of the setting, is typically subject to separate, stricter limits on length of stay compared with care for "physical" health problems. Federal law requires precertification that inpatient services are necessary and can be reasonably expected to improve the patient's condition so that ultimately such services will no longer be necessary (69).

Partial Hospitalization—Partial hospitalization is an often important way of allowing adolescents with mental health problems to spend longer amounts of time (usually 4 hours per day) in a treatment setting (19). Eighteen States cover partial hospitalization, most with no day limits. Some States do not permit partial hospitalization in freestanding psychiatric facilities (19).

Outpatient Mental Health Care—How Medicaid covers outpatient mental health care depends on whether services are provided in a hospital outpatient setting, clinic, or physician or other health provider's office. In 40 States, mental health visits are covered in a general hospital outpatient setting and are usually subject to visit or dollar limits and prior authorization requirements. Twenty-one States cover outpatient mental health services in psychiatric hospitals. Few States restrict the type of therapy used (i.e., individual therapy).

As noted earlier, all but three States cover clinic services. Community mental health centers can

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[74] A more detailed review of State Medicaid coverage of mental health and substance abuse will be available in an upcoming report prepared by Fox, McManus, Wicks, et al., for the Alcohol, Drug Abuse, and Mental Health Administration in the U.S. Department of Health and Human Services (22). The sections on mental health and substance abuse presented here are based largely on a summary of this report.

[75] The 38 States are Alabama, Alaska, Arkansas, California, Colorado, Connecticut, District of Columbia, Hawaii, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Utah, Vermont, Washington, West Virginia, and Wisconsin.

Table 16-14—Coverage of and Restrictions on Hospital Outpatient Services in State Medicaid Programs, 1989[a]

State	Limits on basic coverage	Separate limits for some services (e.g., mental health, ancillary therapies)	Prior authorization required[b]
Alabama	3 visits/year	—	—
Alaska	—	X	X
Arkansas	12 visits/year[c]	—	—
California	—	X	X
Colorado	—	X	X
Connecticut	—	—	X
Delaware	—	—	—
District of Columbia	2 visits/day	—	—
Florida	$1,000/year	—	—
Georgia	—	—	X
Hawaii	—	—	X
Idaho	—	X	—
Illinois	—	—	—
Indiana	—	—	X
Iowa	—	—	X
Kansas	—	X	—
Kentucky	—	—	—
Louisiana	—	—	—
Maine	—	—	—
Maryland	—	—	—
Massachusetts	—	—	X
Michigan	—	—	X
Minnesota	—	—	X
Mississippi	6 visits/year	—	X
Missouri	—	—	X
Montana	—	—	—
Nebraska	—	—	X
Nevada	—	—	X
New Hampshire	12 visits/year	X	—
New Jersey	—	—	X
New Mexico	—	X	X
New York	—	—	X
North Carolina	24 visits/year[d]	X	X
North Dakota	—	—	—
Ohio	—	X	X
Oklahoma	1 visit/day	—	—
Oregon	—	—	X
Pennsylvania	—	X	X
Rhode Island	—	—	X
South Carolina	—	—	—
South Dakota	—	—	—
Tennessee	30 visits/year	—	—
Texas	—	X	X
Utah	—	—	X[e]
Vermont	—	X	—
Virginia	—	—	—
Washington	—	—	X
West Virginia	—	X	X
Wisconsin	—	—	—
Wyoming	—	—	—
Total	9	13	27

[a] Hospital outpatient limits do not apply to services provided under EPSDT.

[b] Prior authorization requires advance approval for some services based on a finding of medical necessity.

[c] All outpatient hospital and physician services.

[d] All outpatient hospital, clinic, and physician services.

[e] Prior authorization required to exceed a limit.

SOURCE: P. McManus, H. Fox, P. Newacheck, et al., unpublished data from a 1989 survey of State Medicaid programs, supported by a grant (# MCH-063500) from the Bureau of Maternal and Child Health and Resources Development, and the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services, Rockville, MD, 1989.

qualify as Medicaid clinics and may provide adolescents the same wide range of mental health services that might be available in a hospital outpatient setting, but in a somewhat less institutionalized atmosphere (19). Benefits in this setting may include assessment/diagnosis; individual, group or family therapy; psychological testing; medication monitoring; and crisis intervention. In 1989, 38 States covered outpatient care provided in a community mental health center; 24 States allowed care in a private mental health center. Services are typically subject to prior authorization or ceilings on visits or dollars spent.

Eligible Providers—Although all States cover physician care, in one out of four States, visits to psychiatrists are subject to separate and more restrictive office visit limits that range from 12 to 48 visits per year. Many State Medicaid programs confine their outpatient mental heath benefits to services provided by or under the supervision of psychiatrists.[76] Almost half of all States do not cover nonphysician mental health providers, such as psychologists and clinical social workers, even if their services are provided under a psychiatrist's supervision. State Medicaid programs that cover independent psychologists usually restrict reimbursement to an outpatient office or clinic setting. Independent clinical social workers are reimbursed by Medicaid only in Massachusetts and Montana.

One survey of State mental health coverage found that 38 State Medicaid programs allowed at least two mental health visits per week at either a hospital outpatient or clinic setting (19). Of these 38 States, most covered weekly visits to psychiatrists, most offered partial hospitalization, and some provided psychologists' services; none reimbursed all three.

Substance Abuse Treatment—As in mental health care, States often set strict limits on Medicaid benefits for substance abuse treatment.

Inpatient Substance Abuse Treatment—All but four States cover alcoholism and drug treatment services in a general hospital inpatient setting. Thirty-four States that cover mental health stays in psychiatric facilities also allow treatment for substance abuse. As for mental health care, however, only 10 of these States allow substance abuse treatment in residential treatment centers and other special psychiatric facilities that are not certified by the Joint Commission on Accreditation of Healthcare Organizations. As many as two-thirds of all States providing substance abuse inpatient care restrict coverage to detoxification only. Five States cover partial hospitalization for treatment of substance abuse usually with restrictions on length of stay.

Photo credit: Sasha Bruce Youth Network, Inc., Washington, DC

Almost half of all State Medicaid programs do not cover nonphysician mental health providers, such as psychologists and clinical social workers, even if their services are provided under a psychiatrist's supervision.

Outpatient Substance Abuse Treatment—Thirty States cover visits to an outpatient hospital department for substance abuse, usually subject to limits on utilization and cost. Twelve States cover outpatient treatment in drug or alcohol abuse clinics. Care may also be covered in community mental health centers.

Physician Reimbursement and Participation Under Medicaid

Even if a poor adolescent holds a Medicaid card that represents a rather rich package of potential health benefits, finding a private physician willing to see Medicaid patients can be a significant problem, especially among some medical specialties and in certain geographic areas (73). Low payment rates,

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[76] Nonphysician mental health providers face similar restrictions in the Medicare program. With one exception (a requirement of the Omnibus Budget Reconciliation Act of 1987 (Public Law 100-203) that stipulates direct payment of psychologists providing services in community mental health centers), Medicare does not allow direct payment of psychologists or any other nonphysician mental health provider (18).

Table 16-15—Factors Cited by Pediatricians as "Very Important" to Decision To Participate in Medicaid

	Percent of pediatricians citing factor as very important			
Factors	1978 N = 814	1983 N = 791	1989 N = 940	Percent change 1978-89
Low payments	59.7	66.5	70.9[a]	18.8%
Unpredictable payments	41.3	52.4	53.4[a]	29.3
Complex regulations	38.6	46.3	47.5[a]	23.1
Payment delays	34.1	34.8	43.4[a]	27.3
Covered services	26.1	31.0	39.8[a]	52.5
Program regulations	29.4	32.8	38.8[a]	32.0
Paperwork	33.7	35.8	38.7[b]	14.8
Broken appointments	29.0	31.1	30.2	4.1
Type of patient	NA	14.8	12.9	–12.8
Few Medicaid eligibles	NA	5.0	4.3	–14.0

NA = not available.

[a] $P < 0.01$.

[b] $P < 0.05$.

SOURCE: B. Yudkowsky, J. Cartland, and S. Flint, "Pediatrician Participation in Medicaid," *Pediatrics* 85(4):567-577, 1990. Reprinted with permission.

administrative burdens, and other factors often discourage physicians from participating in Medicaid.

While research has shown that national physician surveys probably overstate the rate of physician participation in Medicaid, data from these surveys do help identify the specialties and geographic areas where participation is relatively low (73). Overall participation is particularly low among two specialties that are particularly important to adolescents, obstetrics/gynecology (OB/GYN) and psychiatry. Although current data are not available, in 1984 only 60 percent of psychiatrists and 72 percent of OB/GYNs accepted any Medicaid patients at all (73). Given that in recent years many OB/GYNs have withdrawn from obstetrics practice because of malpractice concerns, their Medicaid participation may have declined as well, especially for high-risk patients (52).

A recent survey conducted by the American Academy of Pediatrics found that the proportion of pediatricians saying that they were willing "to see at least some Medicaid patients" declined from 85 percent in 1978 to 77 percent in 1989 (87). Forty-four percent of the surveyed pediatricians reported that they either had refused or limited their availability to care for children with Medicaid coverage in 1989.

Administrative difficulties involved in filing claims for Medicaid reimbursement has consistently been shown to result in lower Medicaid physician participation (52). In the American Academy of Pediatrics survey, pediatricians were asked to identify which factors were "very important" reasons for choosing not to participate or to limit their participation in Medicaid. More than 70 percent cited "low reimbursement" and roughly half also noted "unpredictable payments" and "complex regulations" as a deterrent to their willingness to treat Medicaid children (see table 16-15).[77] Other studies have shown that physicians may find that Medicaid patients require more time and support than others and that they are less likely to follow medical advice (69).

Federal Medicaid rules do not impose specific physician payment methods on State Medicaid programs; Federal rules require only that Medicaid's physician payment level not exceed that paid by the Medicare program for the elderly and that it remain high enough to ensure reasonable access (75). Medicare sets physician payment levels at the 75th percentile of the customary charges in a given locale. Most Medicaid programs use fixed fee schedules that are unrelated to provider charges (69). Medicare permits physicians to bill the patient for charges higher than the Medicare rate, but Medicaid does not allow this. Medicaid reimbursement rates not only vary widely by State but are often far lower than what Medicare reimburses providers. In 1986, for example, maximum Medicaid payment levels for brief followup visits ranged from $6.00 in New Hampshire to $28.41 in Alaska (see table 16-16). As a proportion of local Medicare payment rates, Medicaid fees for followup visits varied from 33 percent in Michigan to 125 percent in Tennessee (69).

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[77] Because of providers' obvious vested interest in improving payment rates, provider surveys inquiring about "low reimbursement" should be viewed with some caution.

Until recently, there has been little effort by the Federal Government to monitor the effect of State Medicaid payment policies on access to care and the availability of qualified providers (75). OBRA-89 took several steps to address this concern. It incorporates into statute the Medicaid regulation requiring that Medicaid payments for all practitioners be "sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area" (11). Yet it should be noted that HCFA staff have described this regulation as an unenforceable "feel good rule" because adequate access is not clearly defined and there is no objective standard for measuring conformity with the law (20). However, States must submit annual plans specifying Medicaid payment rates for obstetrical and pediatric services for the Secretary's review, and in 1992 average Medicaid payments for specific obstetric and pediatric procedures must be reported.

OBRA-89 also directed the Physician Payment Review Commission to examine the adequacy of physician payment, physician participation, and access to care by Medicaid beneficiaries and report to Congress by July 1, 1991. In its initial background report to Congress, the Physician Payment Review Commission concluded that despite recent research focusing on access to care by the uninsured, little attention has been devoted to those individuals already eligible for Medicaid (75). The Physician Payment Review Commission also found that although available studies rely on old data, almost all conclude that higher Medicaid fees result in greater physician participation in the program, even though they used different sources of data (e.g., surveys v. claims records), definitions of participation, and estimation procedures, and appear to apply to all medical specialties (75).

Estimated Effects of Employer Mandates and Medicaid Expansions on the Number of Adolescents Without Health Insurance[78]

"Employer mandates" and Medicaid expansions have been among the numerous legislative proposals suggested to reduce the number of people who lack health insurance in this country. Employer mandates require employers to offer group health insurance policies and pay a significant amount of the premiums for all employees who work more than a specified number of hours per week. Proposals to expand Medicaid require that categorical eligibility requirements be relaxed and/or that income eligibility limits be increased, thereby requiring or encouraging all States to make Medicaid available to all those eligible below certain income levels.

Numerous factors determine the effects of an employer mandate. Who is included in an employer mandate is especially important. How many hours per week must a person work to be considered an employee? Does coverage begin on the first day of employment or after a waiting period? Are the self-employed included? Are employee dependents covered? Will small firms be exempt? What level of benefits must be provided? How much must the employer contribute to the premium?

Similarly, the effect of an expansion in Medicaid depends on a number of policy decisions. For example, what is the minimum eligibility income level? Are the changes in eligibility mandatory or optional for the States? Are two-parent families with workers eligible or must one parent be absent or unemployed?

Estimated Effects of Employer Mandates

The following assumptions were used by OTA in estimating the effect of an employer mandate on the number of uninsured adolescents:

- The self-employed are exempt. All other "permanent" employees who work more than the required number of hours per week are covered (i.e., with no exemptions for firm size or industrial classification).

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[78] The estimates presented here were developed by R. Kronick for OTA, under contract to Carnegie Corporation of New York and the Carnegie Council on Adolescent Development, and are based on U.S. Census Bureau's March 1989 Current Population Survey data (45).

Table 16-16—Comparison of Medicaid and Medicare Reimbursement Rates for a Brief Followup Visit to a Physician Specialist, 1986

	Brief followup office visit (CPT code 90040)		
State	Medicaid maximum payment	Medicare maximum allowable charge	Medicaid as percent of Medicare
Alabama	$11.70	$20.70	56.5%
Alaska	28.41	24.70	115.0
Arkansas	12.00	14.40	83.3
California	11.04	30.00	36.8
Colorado	11.75	15.50	75.8
Connecticut	8.80	24.80	35.5
Delaware	12.66	21.00	60.3
District of Columbia	20.00	25.00	90.9
Florida	10.00	24.80	40.3
Georgia	15.60	15.00	104.0
Hawaii	13.25	16.50	80.3
Idaho	10.50	14.60	71.9
Illinois	11.50	25.00	46.0
Indiana	17.30	16.50	104.8
Iowa	NA	30.00	NA
Kansas	15.00	16.70	89.8
Kentucky	13.00	16.50	78.8
Louisiana	10.69	16.30	65.6
Maine	8.00	NA	NA
Maryland	10.50	22.00	47.7
Massachusetts	8.00	NA	NA
Michigan	7.75	23.50	33.0
Minnesota	15.75	NA	NA
Mississippi	11.55	NA	NA
Missouri	10.00	20.70	48.3
Montana	11.30	14.70	76.9
Nebraska	16.30	16.30	100.0
Nevada	15.82	24.70	64.0
New Hampshire	6.00	12.40	48.4
New Jersey	9.00	20.60	43.7
New Mexico	11.50	17.20	66.9
New York	7.00	20.60	34.0
North Carolina	13.10	16.50	79.4
North Dakota	8.20	12.40	66.1
Ohio	12.00	20.60	58.3
Oklahoma	11.00	20.70	53.1
Oregon	11.07	18.50	59.8
Pennsylvania	13.00	25.00	52.0
Rhode Island	14.00	20.63	67.9
South Carolina	9.50	14.62	65.0
South Dakota	12.00	12.40	96.8
Tennessee	18.00	14.40	125.0
Texas	NA	24.75	NA
Utah	9.92	12.40	80.0
Vermont	8.00	12.40	64.5
Virginia	6.30	NA	NA
Washington	13.92	17.70	78.6
West Virginia	10.00	16.50	60.6
Wisconsin	16.23	18.10	89.7
Wyoming	16.30	14.40	113.2
Simple average	**$12.43**	**$18.56**	**67.0%**

NA = not available.

NOTES: a) Medicaid fees reflect statewide average maximums as reported to HCFA. It is not known which, if any, States have different maximums in different parts of the State. Medicare fees reflect highest allowable charge anywhere in State.

b) Connecticut fee reflects maximum payment for general practitioner; value for specialists is unavailable. District of Columbia fee includes Maryland suburbs. Information on Nevada fees available only for part of State.

SOURCE: U.S. Congress, Library of Congress, Congressional Research Service, *Medicaid Source Book: Background Data and Analysis* (Washington, DC: U.S. Government Printing Office, 1988), pp. 450-451.

Table 16-17—Extending Health Insurance to Uninsured Adolescents:[a] Potential Effect of Three Employer Mandates on Uninsured Adolescents

Uninsured adolescents' living arrangement/ parent's work status	Total number of uninsured adolescents in 1988[a]	Number of uninsured adolescents covered by a mandate covering employees who work at least 30 hours/wk	Additional number covered by changing mandate to cover employees who work at least 25 hours/wk	Additional number covered by changing mandate to 18 hours/wk	Number of uninsured adolescents not covered by a mandate covering employees who work at least 18 hour/wk
Living without parents	862,000	126,000	11,000	32,000	693,000
Parent is self-employed	455,000	7,000	2,000	15,000	432,000
Parent is not working	413,000	5,000	0	3,000	405,000
Parent working fewer than 26 weeks per year	236,000	4,000	0	3,000	229,000
Parent working 26 weeks per year or more	2,645,000	2,404,000	78,000	112,000	51,000
Total	4,611,000 (100.0%)	2,546,000 (55.2%)	90,000 (2.0%)	165,000 (3.6%)	1,810,000 (39.3%)

[a] In 1988, about 4.6 million adolescents ages 10 to 18—15 percent overall—were without health insurance.

SOURCE: R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

- Employees working 26 weeks or more in the preceding year are considered "permanent" workers and are covered under the mandate.
- The effects of the employer mandate are estimated using three different assumptions about the number of hours of work per week at which employees are covered: 18 hours, 25 hours, and 30 hours.
- Adolescents who do not live with their parents are not covered as dependents under the mandate; however, all other unmarried adolescents age 18 or younger are covered by the mandate if their parents were covered as well.

If the employer mandate requires employers to offer health insurance to all employees who work at least 30 hours a week, OTA estimates that approximately 2.55 million uninsured adolescents, or 55 percent of all adolescents currently without health coverage, would become insured (see table 16-17). Reducing the hourly work threshold from 30 hours a week to 25 or 18 hours a week does increase the number of uninsured adolescents who would be covered by health insurance, but its effect is relatively minimal (at least within the range of 18 to 30 hours a week). If the hourly work threshold is reduced to 25 hours per week, for example, an additional 90,000 adolescents (2 percent of all those uninsured) would be covered by health insurance. If the work threshold is 18 hours a week, an additional 165,000 adolescents (or 4 percent of all uninsured adolescents) would be covered.

Estimated Effects of Medicaid Expansions

Proposals to expand Medicaid may either mandate that States broaden Medicaid eligibility or allow States that option. If the current categorical eligibility requirement of a "deprivation factor" is maintained, the potential for an expansion in Medicaid to cover significant portions of uninsured adolescents is severely limited.

If all adolescents living with one parent whose income is below the Federal poverty level were covered by Medicaid, approximately 621,000 of the 4.6 million adolescents without health insurance would be covered (see table 16-18). Even if States were required to extend eligibility standards to all such adolescents, however, it is doubtful that all would enroll. In fact, many of the 8 percent of *uninsured* adolescents who were in single-parent households in 1987, with incomes below 50 percent of poverty, were already eligible to receive Medicaid benefits.

If categorical eligibility requirements were dropped, and all adolescents with family incomes below a specified standard were made eligible for Medicaid, then significant portions of the adolescents without health insurance could be covered by a Medicaid expansion. If Medicaid covered adolescents in families with incomes below 100 percent of poverty, for example, more than 38 percent of currently uninsured adolescents would be covered (see table 16-18). An additional 20 percent of uninsured adolescents would be included if the income standard was raised to 149 percent of poverty.

Table 16-18—Extending Health Insurance to Uninsured Adolescents:[a] Potential Effect of Medicaid Expansions on Uninsured Adolescents

Medicaid income eligibility level[a] [b]	Estimated number (percent) of uninsured adolescents covered by the Medicaid expansion, by adolescent's living arrangement		
	Living with one parent	Living with two parents or living alone	Total
Below 50% of poverty	316,000 (7%)	405,000 (9%)	721,000 (16%)
50 to 99% of poverty	305,000 (7%)	700,000 (15%)	1,005,000 (22%)
100 to 149% of poverty	292,000 (6%)	639,000 (14%)	931,000 (20%)
150 to 199% of poverty	168,000 (4%)	426,000 (9%)	594,000 (13%)
200% of poverty and above	284,000 (6%)	1,077,000 (23%)	1,361,000 (30%)
Total number of uninsured adolescents covered under expansion	1,365,000	3,246,000	4,611,000
Overall percentage of uninsured adolescents covered by expansion	(30%)	(70%)	(100%)

[a] In 1988, about 4.6 million adolescents—15 percent overall—were without health insurance.

[b] Assumes that all adolescents in families with incomes below the specified amount would be covered by Medicaid.

SOURCE: R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

Table 16-19—Extending Health Insurance to Uninsured Adolescents:[a] Potential Effects of Various Combinations of Employer Mandates and Expansions in Medicaid on Uninsured Adolescents

Medicaid income eligibility level[b]	Percent of currently uninsured adolescents who would be insured under the indicated combination of an employer mandate and Medicaid expansion			
	No employer mandate	Employees included in the mandate[c] (no. of hours worked weekly)		
		30 hours	25 hours	18 hours
No expansion	0%	55%	57%	61%
Below 50% of poverty	16	68	69	72
Below 100% of poverty	37	78	79	81
Below 150% of poverty	57	86	87	88
Below 200% of poverty	70	90	91	92

[a] In 1988, about 4.6 million adolescents—15 percent overall—were without health insurance.

[b] Assumes that all adolescents in families with incomes below the specified amount would be covered by Medicaid.

[c] The employer mandates assume that all workers excluding the self-employed (and their dependents), who work more than the indicated number of hours for at least 26 weeks during the preceding year, would be covered.

SOURCE: R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

Combined Approach: Employer Mandate With a Medicaid Expansion

OTA estimates that if employers were required to provide health insurance to all workers who worked at least 18 hours a week and if Medicaid were made available to all adolescents in families with incomes below 200 percent of the poverty level, then only 8 percent of adolescents without health insurance would remain uninsured (see table 16-19). An employer mandate that included employees who worked at least 30 hours per week combined with a Medicaid expansion that included all adolescents below 100 percent of poverty would leave 22 percent of currently uninsured adolescents without health insurance.

Most of the adolescents left out by the combination of an employer mandate and Medicaid expansion are children of the self-employed. If the self-employed were included under a "combination" mandate, nearly all currently uninsured adolescents would be covered.

Of the proposals evaluated, clearly the single greatest impact on uninsured adolescents would come from an employer mandate.

Conclusions and Policy Implications

Adolescents Without Health Insurance

In 1988, about 4.6 million U.S. adolescents—or one out of seven overall—lack a key ingredient to access to health care: health insurance coverage. That health insurance coverage and ability to pay may determine when, or if at all, someone seeks medical services is well established. It has also been shown that while people with incomes below the Federal poverty level have significantly fewer physician contacts than others in the same state of health, Medicaid coverage can counter these effects of poverty. Yet one out of three poor adolescents ages 10 to 18 is not covered by the Medicaid program. And few adolescents except those who are pregnant have benefited from recent Medicaid expansions. Family income is clearly the most important determinant of health insurance status. But many adolescents in nonpoor families, including a significant proportion with working parents, also lack health insurance. Adolescent children of parents who work for small firms or are self-employed are especially at risk; approximately one out of four is uninsured, and adolescents in this group account for more than half of all uninsured adolescents. Overall, the percentage of the nonelderly population without health insurance is particularly high in the South and West, although only in eight States do 90 percent of residents have health insurance.

Ninety-four percent of adolescents ages 10 to 18 live with one or both parents, and the majority of them are covered by a parent's employer-sponsored health plan. But there is increasingly worrisome evidence that escalating health insurance costs are threatening coverage of adolescents and other dependents of the working insured. More workers than ever before are required to pay a higher share of insurance premiums to cover their dependents, and some receive no financial contribution from their employers for family benefits. The U.S. General Accounting Office recently found that, for lower income families, the high cost of family coverage can lead to decisions to forego dependent coverage altogether (67). In 1989, premiums for employer-sponsored health insurance for family coverage rose 18 percent and cost, on average, more than $260 per month; parents paid an average share of $55 to $81 per month depending on the type of plan. Deductibles and coinsurance requirements for *covered* benefits typically add annual out-of-pocket costs of up to $2,000 per family for "physical" health problems; cost-sharing for mental health care and *uncovered* services can be an additional expense. Recent surveys of employers reflect their growing concern about the cost burden of covering their employees' dependents. Many employers report that they intend to increase their employees' share of premium costs, deductibles, and copayments. Some employers plan to cut benefits for dependents.

Most approaches to resolving the dilemma of the uninsured have focused on the overall nonelderly population, and no attention has been given to addressing the health coverage needs of adolescents in particular. Numerous commissions and studies have looked at a wide range of remedies to improve the plight of the uninsured including national health insurance proposals, employer mandates to provide health benefits to workers and their dependents, Medicaid expansion and reform, tax reform, and regulatory reform of employee health benefit plans and private health insurance (3,17,37,56,74). OTA does not endorse any particular approach but examined the effects on adolescents of combining two generic proposals: 1) an expansion in Medicaid to cover all adolescents whose families have incomes below the Federal poverty level and 2) a mandate to employers to provide health benefits to all workers (and their families) working at least 30 hours weekly. Such an approach would insure approximately 78 percent of uninsured adolescents ages 10 to 18.

At a minimum, the Federal Government should consider efforts to prevent any erosion in employer-sponsored health benefits for adolescent dependents, especially for critical health care needs such as treatment of acute and chronic illnesses, mental health care, substance abuse treatment, maternity care and related services (including family planning), vision and dental care, and rehabilitative services. Congress could act to maintain current private health insurance benefits for adolescent dependents by prohibiting employer-sponsored health plans from providing more limited benefits to health plan participants (i.e., subscriber or dependent) based on age or coverage status.

As private health insurance benefits have not been developed or assessed with respect to the special needs of the adolescent population, Congress could also support an effort to develop a model health insurance benefit for adolescents.

Adolescents With Private Health Insurance

Although adolescents with private health insurance have a wide range of benefits, their health plans may not meet some crucial adolescent health needs. Health benefits surveys show that 90 percent or more of employees with employer-based group health coverage have health benefits for hospital room and board, surgical services, physician visits, diagnostic X-ray and laboratory procedures, and outpatient prescription drugs. Mental health and substance abuse benefits are also available in most plans, but they are subject to separate and more stringent limitations than for "physical" problems. Preventive services, including basic immunizations and routine health assessments, are usually not covered for adolescents by private health plans, with the exception of health maintenance organizations. Most privately insured adolescents do not have basic dental, hearing, and vision benefits.

Approximately one-third of privately insured adolescents are not covered for maternity-related services because of a loophole in the Pregnancy Discrimination Act of 1978 (Public Law 95-555) that allows employers not to cover maternity care for adolescent daughters of employees in their health benefit plans. Congress should consider amending the act to close this loophole.

While it is not clear that physical and mental health care should be covered in precisely the same manner, there is evidence that current mental health benefits may lead to inappropriate hospitalization of adolescents and that the preferred approach to treatment, community- and family-based care, is often strictly limited or not covered at all. In addition, recent surveys of employers who provide health benefits indicate that coverage of mental health and substance abuse treatment for adolescent dependents may be in jeopardy. Inpatient treatment costs for mental health and substance abuse for adolescents are often substantially higher than for adults, and employers are finding that a rising share of their claims dollars are going towards the mental health and substance abuse care of their workers' children. As a result, many employers and health insurers are now reconsidering how and whether to cover mental health and substance abuse treatment for dependents. In fact, a recent survey of corporate benefits decisionmakers found that more than half predicted restricting or excluding coverage for dependent mental health or chemical dependency illnesses. Congress could support an effort to develop a model health insurance benefit for mental health and substance abuse treatment for adolescents. It could also act to prevent any future erosion of benefits for adolescent dependents by requiring equivalent benefits for mental health and substance abuse for all recipients of employer-sponsored health benefits regardless of age or coverage status (i.e., subscriber or dependent).

Little is known about the extent to which private health insurance reimburses nonphysician providers who are often key players in adolescent health settings, such as school-based clinics. How nurse practitioners, psychologists, clinical social workers, and drug addiction counselors are paid for their services can be critical to the development of additional low-cost community adolescent health care resources. Although many States mandate private health insurance coverage of some nonphysician providers, especially psychologists, social workers, nurse practitioners, and clinical nurse midwives, it is not clear how many health insurance plans allow for direct payment for their services since a substantial proportion of employment-based health coverage is free from State insurance regulation. The quality of care provided by nurse practitioners and clinical nurse midwives within their areas of competence is equivalent to that provided by physicians, and these caregivers can be cost-effective substitutes for physicians in delivering many services (72). Under OBRA-89, State Medicaid programs are now required to cover certified pediatric and family nurse practitioners to the extent that they are legally authorized by State law to provide services even if they are not practicing under the supervision of, or associated with, a physician or other provider. Medicaid also mandates coverage of clinical nurse midwife services. Congress could act to mandate private insurance coverage of nurse practitioners and clinical nurse midwives to boost the availability of personnel to treat adolescents and the financial viability of school-linked and other adolescent health centers.

Adolescents in the Medicaid Program

The Medicaid program may be more aptly described as a confederation of 50 State programs. Although Federal guidelines determine broad eligibility and coverage criteria, each State designs and manages its own Medicaid program. Consequently, eligibility requirements, services offered, utilization limits, and provider payment policies vary widely among the States. How well Medicaid covers poor adolescents depends to a large extent on these State-specific features.

Medicaid is a joint Federal-State entitlement program and its costs are shared by Federal and State Governments. The Federal share in each State's Medicaid program ranges from 50 to 80 percent, and in fiscal year 1990 total expenditures were projected to total approximately $70.5 billion. Federal funds account for 56.9 percent of total Medicaid program expenditures, an estimated $40.2 billion in fiscal year 1990. Although actual data on Medicaid expenditures for adolescents are not available, HCFA estimates that adolescents ages 10 to 18 made up 17.1 percent of Medicaid enrollment and 6.9 percent of overall Medicaid expenditures in fiscal year 1988.

One reason that so many poor adolescents are not covered by Medicaid is that eligibility has generally been linked to participation in the AFDC cash welfare program. AFDC eligibility hinges on not only whether family income and resources fall within the State's AFDC limits but also, with few exceptions, whether the family has a so-called "deprivation factor" (i.e., at least one parent is dead, disabled, continually absent from the home, or, as of October 1990, in two-parent families whose principal breadwinner is unemployed). In many cases, the States have failed to adjust the AFDC income standards for inflation and, consequently, the average income threshold as a percentage of the Federal poverty level has been eroded substantially, from 71 percent in 1975 to 47 percent in January 1990.

OTA estimates that if AFDC categorical requirements were dropped and all adolescents with family income below 100 percent of poverty were eligible for Medicaid, then approximately 1.7 million poor adolescents (38 percent of those currently uninsured) would be affected. If the current categorical requirement of a "deprivation factor" is maintained, the potential for an expansion in Medicaid to cover significant portions of poor, uninsured adolescents is severely limited. If all adolescents in single-parent households with incomes below 100 percent of poverty were covered by Medicaid, OTA estimates that approximately 621,000 adolescents would be covered. Congress could expand Medicaid by mandating State benefits to all adolescents through age 18 with family incomes up to 100 percent of poverty or include, as it has for children up to age six, all adolescents up to 133 percent of poverty.

As part of OBRA-89, Congress significantly expanded adolescents' and other children's access to Medicaid-covered services by its reform of the EPSDT program. Under EPSDT, States are mandated by Federal law to periodically screen Medicaid-eligible adolescents for any illnesses, abnormalities, or treatable conditions and refer them for definitive treatment. The OBRA-89 amendments dramatically broadened Medicaid coverage of children and adolescents by essentially eliminating any State Medicaid limitations on diagnosis or treatment for any health condition identified during the course of an EPSDT screen as long as the services are within the limits of Federal Medicaid guidelines and are deemed medically necessary. The potential for providing comprehensive health services using EPSDT will not be fully realized, however, if adolescent Medicaid recipients do not get screened. Although the program has been shown to improve children's health and reduce health care costs, use of EPSDT services is extremely low, especially in rural areas. In fiscal year 1988, average program expenditures were only $9 per Medicaid enrollee age 20 and younger, and were directed largely towards younger children. HCFA estimates that while, in fiscal year 1988, average per enrollee expenditures for EPSDT screening were $15 per child under age 5, they were only $4 for adolescents ages 10 to 14 and $3 for adolescents ages 15 to 18. Congress could act to provide direct subsidies to EPSDT outreach programs that make effective efforts to involve adolescents in EPSDT.

Even if a poor adolescent holds a Medicaid card that represents a rather rich package of health benefits, finding a private physician willing to see Medicaid patients can be a significant problem especially among some medical specialties and in certain geographic areas. Low payment rates, excessive administrative burdens, as well as other factors often discourage physicians from participating in Medicaid. Overall participation is particularly low among two specialties that are particularly important to adolescents, OB/GYN and psychiatry. OBRA-89 directed the Physician Payment Review Commission to examine the adequacy of physician payment, physician participation, and access to care by Medicaid beneficiaries and report to Congress by July 1, 1991. In considering potential Medicaid physician payment reform resulting from the Physician Payment Review Commission effort, Congress could give high priority to providers involved in direct service to adolescents.

Conflict Between Confidentiality and Insurance Reimbursement[79]

Even if appropriate benefits are available, adolescents who are concerned about confidentiality may be reluctant to seek care from providers if their private health plan requires parents to submit a claim for reimbursement (as most do). An adolescent with Medicaid coverage who must present a parent's Medicaid card to gain access to care faces the same dilemma. It may be important to evaluate the feasibility of direct funding of some particularly sensitive adolescent health services, such as pregnancy testing and early prenatal care, mental health and substance abuse counseling.

Summary of Policy Implications

- Congress could act to maintain current private health insurance benefits for adolescent dependents by prohibiting employer-sponsored health plans from providing more limited benefits to health plan participants (i.e., subscriber or dependent) based on age or coverage status. It could also support an effort to develop a model health insurance benefit for adolescents.
- Congress could consider amending the Pregnancy Discrimination Act of 1978 (Public Law 95-555) to close the loophole that allows employers not to cover maternity care for adolescent daughters of employees in their health benefit plans.
- Congress could support an effort to develop a model health insurance benefit for mental health and substance abuse treatment for adolescents. It could also act to prevent any future erosion of benefits for adolescent dependents by requiring equivalent benefits for mental health and substance abuse for all recipients of employer-sponsored health benefits regardless of age or coverage status (i.e., subscriber or dependent).
- Congress could act to mandate private insurance coverage of nurse practitioners and clinical nurse midwives to boost the availability of personnel to treat adolescents and the financial viability of school-based clinics and other adolescent health centers.
- Congress could expand Medicaid by mandating State benefits to all adolescents through age 18 with family incomes up to 100 percent of the Federal poverty level or include, as it has for children up to age 6, all adolescents up to 133 percent of the poverty level.
- Congress could act to provide direct subsidies to EPSDT outreach programs that make effective efforts to involve adolescents in EPSDT.
- Congress could give high priority to providers involved in direct service to adolescents in considering any potential Medicaid physician payment reform that results from the Physician Payment Review Commission's OBRA-89-mandated effort to examine the adequacy of physician payment, physician participation, and access to care by Medicaid beneficiaries.
- Congress could consider direct funding of some particularly sensitive adolescent health services, such as pregnancy testing, early prenatal care, and mental health and substance abuse counseling.

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Chapter 17

CONSENT AND CONFIDENTIALITY IN ADOLESCENT HEALTH CARE DECISIONMAKING

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Chapter 17

CONSENT AND CONFIDENTIALITY IN ADOLESCENT HEALTH CARE DECISIONMAKING[1]

Introduction

Who should decide whether an adolescent is provided health services, what health services are provided, and how health services are provided? The adolescent? The adolescent's parents or legal guardian? Health professionals? The state? And who should decide whether adolescents' communications with health professionals and health care records are to be treated as confidential?

The question of how authority for adolescent health care decisionmaking should be allocated has been much debated—and is far from being settled. The body of law that determines how this authority is allocated—including the extent of parental involvement in adolescent health care decisionmaking—is summarized in this chapter. That body of law is large and complicated and is not always clear or consistent, in part because it is an amalgam of decisions of State and Federal courts, statutes passed by Congress and State legislatures, and regulations issued by executive departments and agencies.

The common law rule—to which there are many notable exceptions identified in this chapter—is that parental consent is generally required for the medical or surgical care of a minor child (i.e., a son or daughter who has not reached the age of majority, either age 18 or 19, depending on the State). The rationales for parental consent requirements are several. One rationale is that minors lack the capacity to make their own health care decisions and need to be protected from their own improvident decisionmaking. The legal presumption that minors are incompetent rests at least in part on an assumption of courts and legislators that minors as a class lack the requisite capacity to make health care decisions for themselves. Recently, the factual validity of that assumption has been increasingly criticized on the ground that it inequitably denies minors in middle or late adolescence—many or most of whom may actually have the requisite decisionmaking capacity—the power to make their own decisions about services. Several empirical studies that challenge the legal presumption about the incompetency of minors to make health care decisions are summarized in the second part of this chapter.

It is important to recognize, however, that concerns about adolescents' competency to make decisions are not the only rationale for parental consent requirements. Several other rationales for such requirements are reviewed in the discussion that follows, among them the state's interest and families' interest in encouraging family involvement in minors' lives and health care providers' interest in being able to receive compensation for the services they provide to minors.

How the law should allocate authority for making decisions about adolescent health care has traditionally been a matter for the individual State governments to determine, but the allocation of authority is or can be controlled or influenced to some extent by the Federal Government acting through the Federal courts, Congress, and Federal agencies. If it chose to, Congress could increase the Federal Government's role in the formulation of more uniform or coherent policies pertaining to the allocation of authority for adolescent health care decisionmaking. That and other possibilities are discussed, and a conceptual framework for public policy formulation in allocating authority for adolescent health care decisionmaking is presented, in the concluding section of this chapter.

Law Pertaining to Consent and Confidentiality in Adolescent Health Care Decisions

The large and complicated body of law that determines the allocation of authority for adolescent health care decisionmaking is summarized below.[2] Much of the law focuses on the nature and extent of parental involvement in adolescent health care decisionmaking, including whether an adolescent's parents must *consent* to the delivery of health services to the adolescent and whether an adolescent's parent must be *notified* of the adolescent's decision to obtain health services or of the adolescent's actual receipt of health services.

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[1] This chapter is based on a February 1990 background paper entitled "Adolescent Health Care Decisionmaking: The Law and Public Policy," prepared for OTA's Adolescent Health Project under contract to the Carnegie Council on Adolescent Development by J. Gittler, M. Quigley-Rick, and M.J. Saks. That background paper has been published separately in its entirety, including extensive legal citations, and is available from the Carnegie Council on Adolescent Development, Washington, DC, or from OTA.

As noted in the introduction, the body of law that determines the allocation of authority for adolescent health care decisionmaking is not always clear or consistent, in part because it is an amalgam of principles and rules drawn from different areas of law (e.g., tort law, contract law, family law, and constitutional law) and different jurisdictions, and in part because it consists of decisions of Federal and State courts, statutes passed by Congress and State legislatures, and regulations issued by executive departments and agencies. For at least some adolescents, a lack of information about what services they can or cannot receive without parental consent or notification may be a barrier to their seeking or receiving certain types of health services. For other adolescents, the barrier may be the substance of the laws requiring parental consent or notification rather than confusion about what the law allows.

Parental Consent Requirements

Anglo-American law draws a sharp distinction between adults and minors, and it is well established that minors have fewer rights and more restrictions on their liberty than adults (27,33). It is also well established that parents have a right to care, custody, and control of their minor children (83). Perhaps not surprisingly, therefore, the common law rule is that parental consent is generally required for the medical or surgical care of a minor child.[3] The age of majority is determined by individual States. Currently, the age of majority is set at age 18 in every State but Alaska, Nebraska, and Wyoming, where the age is 19. States can modify the age of majority to confer upon minors rights normally reserved for adults, and five States (Alabama, Kansas, Rhode Island, South Carolina, and Oregon[4]) have enacted statutes that specifically authorize minors who have reached a designated age—ranging from 14 to 16—to consent to health care.

The parental consent requirement reflects the application to minors of the tort law doctrine of informed consent, as well as principles under contract law. As discussed later in this chapter, the legal doctrine of informed consent is based on the premise that every person has the right to determine what is done to his or her own body. The doctrine of informed consent holds, therefore, that physicians and surgeons have a duty to give their adult patients the information necessary for making an informed and voluntary choice concerning medical treatment or surgery; the failure by a physician or surgeon to obtain informed consent from a patient may give rise to a civil liability and an award of damages.[5] In addition, under contract law, the relationship between a doctor and an adult patient is usually considered a contractual relationship. Among the essentials of any contract are competent parties.

Traditionally, minors have been deemed incompetent as a matter of law to give informed consent to medical and surgical care and incompetent to enter into binding contracts, including contracts with physicians and surgeons. Thus, parental consent has been required for provision of health services to minors.

The rationales for parental consent requirements in the area of health care are several. One of the main rationales for the parental consent requirement—based on the assumption that minors lack the requisite capacity to make health care decisions—is the need to *protect minors from their own improvi-*

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[2] Although the focus of this OTA Report is on "adolescents" defined as individuals ages 10 to 18, the law regards 10- to 18-year-olds not as "adolescents" but as either "minors" or "adults." Since 18-year-olds are legally considered adults in all but three States, most of the issues about adolescent health care decisionmaking raised in this chapter pertain to adolescents ages 17 and under.

[3] See, for example, *Bonner* v. *Moran*, 75 App. D.C. 156, 126 F.2d 121, 123 (D.C. Cir. 1941); *Rogers* v. *Sells*, 178 Okla. 103, 61 P.2d 1018 (1936); *Browning* v. *Hogan*, 90 W. Va 568, 111 S.E. 492 (1922). See Institute of Judicial Administration and American Bar Association, Juvenile Justice Standards Project, *Standards Relating to Rights of Minors* (47); G.D. Dodson, "Legal Rights of Adolescents: Restrictions on Liberty, Emancipation, and Status Offenses" (33); and R. Bennett, "Allocation of Child Medical Care Decision-Making Authority: A Suggested Interest Analysis" (19).

[4] ALA. CODE § 22-8-4 (1984); KAN. STAT. ANN. § 38-123b (1986); R.I. GEN. LAWS § 23-4. 6-1 (1985); S.C. CODE ANN. § 20-7-280 (Law. Co-op. 1985); OR. REV. STAT. § 109.640 (1981).

[5] The law of torts protects persons against unauthorized bodily invasion. Bodily contact with a patient by a physician or surgeon without the patient's consent constitutes technical battery, which is a tort (53).

dent decisionmaking.[6] Accepting for the sake of argument that minors in fact need protection from their own improvident decisionmaking, there remains the question of why *parents* have been legally authorized to make health care decisions on behalf of their minor children. There appear to be two operative premises in this regard: 1) that parents, in contrast to their minor children, possess the intelligence, maturity, and experience needed for adequate and appropriate health care decisionmaking; and 2) that parents usually have an identity of interest with their minor children and will act in their best interests. In at least some situations, parents and their adolescent children do not have an identity of interest, and sometimes their interests may conflict.[7] It is precisely such situations that give rise to concerns that parental consent or notification requirements may create barriers to adolescents' seeking or receiving certain types of health services.

Another rationale for the parental consent requirement—apart from the need to protect minors from their own improvident decisionmaking—is a belief that the parental consent requirement *promotes family autonomy*[8] *and privacy and promotes parental authority*[9] *and control of minor children.* Family autonomy and parental authority, in turn, are often viewed as fostering the stability and cohesiveness of the family as an institution and of individual family units. The U.S. Supreme Court has commented in a series of decisions on the importance of family autonomy and parental authority, and the Court has extended Federal constitutional protection, albeit not absolute protection, to family autonomy and parental authority.[10] The parental consent requirement also seems, at least somewhat, to be designed to protect parents from financial liability arising from the provision of health services, without their consent, to their children and to ensure providers of the availability of a payment source for the services they provide to minors.

Exceptions to the Parental Consent Requirement

Over the years, the number of exceptions to the parental consent requirement applicable to the health care of minors has grown significantly. Exceptions to the parental consent requirement, described below, tend to fall into four categories:

- exceptions arising out of the jurisdiction of juvenile and family courts over abused and neglected minors,
- exceptions related to the status and characteristics of individual minors (e.g., emancipated, independent, or mature minors),

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[6] In dealing with issues of consent to health care for minors, State courts and lower Federal courts have consistently expressed concern about the decisionmaking capabilities of minors. In *Bonner* v. *Moran*, 75 App. D.C. 156, 126 F.2d 121, 122 (1941), for example, the court stated: "In deference to common experience, there is general recognition of the fact that many persons by reason of their youth are incapable of intelligent decisions, as a result of which public policy demands legal protection of their personal as well as their property rights." In recent years, the U.S. Supreme Court, in dealing with issues concerning access of minors to contraceptives and abortions and the civil commitment of minors, has similarly expressed concern about the decisionmaking capabilities of minors. For example, in *Parham* v. *J.R.*, 442 U.S. 584, 602, 603 (1978), the court stated: "Most children, even in adolescence, simply are not able to make sound decisions, including their need for medical care or treatment." See also *Bellotti* v. *Baird*, 443 U.S. 622, 633, 640 (1978), reh. denied, 444 U.S. 887 (1979); *Planned Parenthood of Missouri* v. *Danforth*, 428 U.S. 52, 91 (1976) (Stewart, J., concurring); *Carey* v. *Population Services International*, 431 U.S. 678, 709 (1977) (Powell, J. concurring); *Carey* v. *Population Services International*, supra at 714 (1977) (Stevens, J. concurring).

[7] For a further discussion of how the interests of an adolescent, the adolescent's parents, the state, and health providers may differ, see box 17-B in the concluding section of this chapter.

[8] *Family autonomy* refers to noninterference by the state in the right of families to make important decisions concerning family life and family members. A tradition of family autonomy is deeply imbedded in Anglo-American law and can be traced back to Roman law, the Judeo-Christian tradition, and Anglo-Saxon customary law. Family autonomy is often but not always equated with parental authority (42).

[9] *Parental authority* refers to the deference of the state to the right of parents to make childrearing decisions (42). At common law, minor children were in effect the chattels or property of their parent, who had virtually the unfettered right to rear them as they saw fit. Over time, minor children increasingly have been recognized as having independent rights (45), yet they are still largely subject to the authority of their parents.

[10] In a line of decisions over 50 years, the U.S. Supreme Court has held that parents have a Federal constitutional right to direct the upbringing of their children free from state intervention in the absence of a constitutionally acceptable justification for such intervention. The Court's most notable decisions in this regard are *Meyer* v. *Nebraska*, 262 U.S. 390 (1923); *Pierce* v. *Society of Sisters*, 268 U.S. 510 (1925); *Prince* v. *Massachusetts*, 321 U.S. 158 (1944); and *Wisconsin* v. *Yoder* 406 U.S. 205 (1972). See also *Ginsburg* v. *New York* 390 U.S. 629. 634 (1968), reh. denied, 391 U.S. 971 (1973). In another line of decisions, the U.S. Supreme Court has afforded minors some of the same constitutional rights that adults are afforded in areas that do not directly implicate parents' right to direct the upbringing of their children. See, for example, *In re Gault*, 387 U.S. 1 (1967); *Tinker* v. *Des Moines Independent Community School District*, 393 U.S. 503 (1969); and *Goss* v. *Lopez*, 419 U.S., 565 (1975). In recent years, the U.S. Supreme Court has begun to confront conflicts between a parent's asserted right to direct the upbringing of his or her minor child and the minor's assertion of his or her own independent rights and has issued several decisions involving actual or potential parent-child conflicts with respect to the access of minors to contraceptives and abortions and the civil commitment of minors. Taken as a whole, however, the results and rationales of the Supreme Court's decisions do not reflect a coherent approach to such conflicts.

- exceptions for health emergencies, and
- exceptions for specific health problems and services (e.g., services related to sexual activities, drug and alcohol abuse, or mental health).

As noted in the discussion that follows, some of the exceptions apply to certain categories of minors regardless of their age, and others are directed at or affect primarily adolescent minors. For a number of exceptions to parental consent requirements for specific health problems, as will be discussed later, there are now in place parental notification requirements.

Exceptions Arising From Juvenile and Family Courts' Jurisdiction Over Abused and Neglected Minors

In all States, juvenile and family courts have jurisdiction over minors of all ages who have been abused or neglected. Exercising this jurisdiction, juvenile and family courts have traditionally had the power to intervene to secure health services for minors whose parents refuse to consent to the provision of services if the parents' refusal is deemed medical neglect. The basis for judicial intervention under State juvenile and family court acts in such instances is the state's parens patriae power. In many instances where medical neglect is alleged, the parents' refusal to consent to care is based on religious convictions. Judicial intervention typically occurs only when a minor's life is or will be threatened because of lack of care.

Exceptions Related to the Status and Characteristics of Individual Minors

Two major types of exceptions to the parental consent requirement are related to the status and characteristics of individual minors:

- exceptions for "emancipated" minors and "independent" minors, and
- exceptions for "mature" minors.

Exceptions for "Emancipated" and "Independent" Minors—Emancipation is a somewhat murky and confused area of the law,[11] but generally speaking, "emancipated minors" are minors who have been legally freed from the control and authority of their parents. Under the common law doctrine of emancipation, courts—without explicit statutory authorization—may use various factors in determining whether a minor's emancipation has taken place. Emancipation may be found to have occurred in accordance with an express agreement between a minor's parents and the minor or may be implied from the acts of the minor's parents and the minor. The main indicia of emancipation implied from the acts of the parties are a minor's marriage, a minor's induction into the armed services, a minor's establishment of a home away from that of his or her parents, a minors' economic independence from his or her parents, and a minor's age (50). Emancipation under common law may be complete or partial and may or may not result in a minor's having the right to consent to health services.

About half of the States have enacted statutes that provide for court-ordered emancipation of minors or specify that certain designated acts by a minor's parents, a minor, or both constitute emancipation. Some of these statutes explicitly state that emancipation under these statutes removes the disabilities of minority, including the requirement of parental consent to health services. Thus, minors emancipated under these statutes have the right to consent to health services.

A substantial number of States have enacted statutes that authorize minors who have attained varying degrees of *independence* to consent to health services but that do not use the term "emancipation" or "emancipated" minors. Over half of the States have "independent minor" statutes that allow minors who are parents to consent to health care for themselves and/or their children; about half of the States have statutes that allow married minors to consent to health care; and some States have statutes that allow independent minors in other categories (e.g., minors living apart from their parents and managing their own financial affairs, minors in the military, minors who are high school graduates) to consent to health services.

Emancipated minor and independent minor exceptions to the parental consent requirement affect minors who have achieved complete or substantial independence from their parents, so they primarily affect adolescent minors. The focus of these exceptions is the minor's independence, not the minor's capacity to make health care decisions. These exceptions seem to reflect legislative judgments that a minor who is not part of a functioning family, or whose parents exercise little or no control over him or her, is in a better position to make health care decisions than the minor's parents.

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[11] For discussions of the origins and development of emancipation, see H.H. Clark, *The Law of Domestic Relations in the United States* (27); F. Cady, "Emancipation of Minors" (24); and S. Katz, W. Schroeder, and L. Sidman, "Emancipating Our Children—Coming of Age in Legal America" (50).

Exceptions for "Mature" Minors—The "mature minor" exception to the parental consent requirement has been enunciated primarily by courts rather than by State legislatures. This exception was recognized by State courts beginning in the early 1900s. According to one authority, the factors supporting a determination of a minor's maturity for purposes of health care decisionmaking in these decisions are as follows:

> (1) the treatment is undertaken for the benefit of a minor rather than a third party; (2) the particular minor is near the age of majority; (3) the minor is considered to have sufficient mental capacity to understand fully the nature and importance of medical steps proposed; (4) the procedures are characterized as less than "major," not "serious" or not overly "complex" (75).

Recently, the mature minor doctrine has been applied by the U.S. Supreme Court in decisions dealing with the right of a minor to family planning services and abortion services (see discussion below). Only a few States have mature minor statutes. Three States (Arkansas, Mississippi, and New Hampshire[12]) have enacted statutes that explicitly authorize mature minors to consent to health services, and two States (Idaho and Nevada[13]) have enacted statutes that are somewhat ambiguous but could be construed to constitute mature minor consent statutes.

The mature minor exception to the parental consent requirement is based on a rejection of the presumption of minors' incompetency and the underlying assumption that minors as a class lack decisionmaking capacity; this exception allows for individualized determinations of minors' actual decisionmaking capacity. Because it pertains to mature minors, this exception to the parental consent requirement probably most often applies to minors in middle and late adolescence.

Exceptions for Health Emergencies

In health emergencies, medical or surgical care may be furnished to minors without parental consent. The emergency exception to the parental consent requirement was originally enunciated by the courts. More than half of the States now have statutes that codify the exception. Some of the State statutes simply authorize emergency care of a minor without parental consent; others state that a physician or other health professional who treats a minor in an emergency without parental consent is relieved from liability; and still others provide that a minor may consent to emergency care.

Exceptions for Specific Types of Health Services

Exceptions to the parental consent requirement for specific health problems or specific types of services fall into three major categories:

- exceptions for health services related to sexual activities,
- exceptions for health services related to drug and alcohol abuse, and
- exceptions for mental health services.

Exceptions for Health Services Related to Sexual Activities—Exceptions to the parental consent requirement for health services related to sexual activities are of three general types: 1) exceptions for health services related to venereal,[14] sexually transmitted, and infectious diseases and acquired immunodeficiency syndrome (AIDS); 2) exceptions for family planning services and abortion services; and 3) exceptions for pregnancy-related health services.[15]

Exceptions for Health Services Related to Venereal, Sexually Transmitted, and Infectious Diseases and AIDS—Almost all States have enacted legislation that specifically allows minors to consent to or to receive services for a venereal or sexually transmitted disease without parental consent. More than two-thirds of the States have enacted legislation that specifically allows minors to obtain without parental consent health services for "venereal disease"; about one-quarter of the States have a statute that allows services without parental consent for "sexually transmitted disease." A few States have a statute that allows minors to obtain services without parental consent for "infectious, contagious, communicable and reportable diseases" (or some variant thereof). None of the State statutes just mentioned expressly covers testing for infection with human immunodeficiency virus (HIV), the virus that causes AIDS, but some of them may cover or could be interpreted to cover HIV testing. A few States have statutes that expressly authorize minors to consent to or to receive HIV testing without parental consent.

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[12] ARK. CODE ANN. § 20-9-602(7) (1987); MISS. CODE ANN. § 41-41-3(h) (Supp. 1988); N.H. REV. STAT. ANN. § 318-B:12a (1984).

[13] IDAHO CODE § 39-4302 (1985); NEV. REV. STAT. § 129.030(2) (1987). But see NEV. REV. STAT. § 129.030(1) (1987).

[14] In common usage, the term "venereal disease" has been replaced by "sexually transmitted disease" (see ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services," in Vol. II. However, because some State statutes use the older term venereal disease, it is included here.

[15] The effectiveness of services related to adolescents' sexual behavior—e.g., services for the prevention and treatment of AIDS and other sexually transmitted diseases, family planning services, and pregnancy-related services—is discussed in Vol. II in ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services," and ch. 10, "Pregnancy and Parenting: Prevention and Services."

Most of the State statutes just mentioned allow minors of any age to consent to services or to receive services for the diseases specified without parental consent, although others specify that minors must be 12 or 14 to consent to these services. The fact that these statutes impose either no age limit or a very low age limit for minors to consent to or to receive services for these diseases without parental consent appears to stem from a legislative recognition that society has a critical interest in facilitating and encouraging access to health services to reduce the spread of disease among its citizens.

Exceptions for Family Planning Services[16] *and Abortion Services*—Restrictions on access to family planning services and abortion services by adolescents are governed by Federal constitutional law as interpreted by the U.S. Supreme Court and the lower Federal courts, and the Supreme Court is the final arbiter of what is constitutionally permissible and impermissible when it comes to State-imposed restrictions—including parental consent and notification requirements—on the provision of family planning services and abortion services to minors.

In the landmark 1965 case *Griswold* v. *Connecticut* [381 U.S. 479 (1965)] and in *Eisenstadt* v. *Baird* [405 U.S. 438 (1972)], the U.S. Supreme Court held that an individual has a constitutionally protected "right to privacy" under the 14th amendment encompassing decisions with respect to the use of contraceptives.[17] In the 1977 case *Carey* v. *Population Services International* [431 U.S. 678 (1977)], the U.S. Supreme Court established that minors as well as adults have a constitutionally protected right to privacy with respect to the use of contraceptives.[18] A little under half of the States have statutes providing that minors may obtain without parental consent what are variously described as contraceptives, birth control services, or services for the prevention of pregnancy. Some of these statutes impose restrictions on minors' obtaining these services without parental consent (e.g., that the minor be of a certain minimum age, be referred from a designated source, possess a certain maturity and intelligence, or be likely to suffer detrimental health consequences if the services are not provided). Many of them explicitly exclude or have been or could be interpreted as excluding abortion from the services that minors may obtain.

In the landmark 1973 decision *Roe* v. *Wade* [410 U.S. 113 (1973)], the U.S. Supreme Court held that the constitutional right to privacy encompassed a woman's decision about whether to have an abortion and invalidated State criminal statutes prohibiting nontherapeutic abortions at any stage of pregnancy. At the same time, however, the Court ruled that a State did have legitimate interests (e.g., in safeguarding maternal health, in maintaining proper medical standards, and in protecting human life) that could justify State regulation of the performance of abortions.[19]

Since 1972, the Supreme Court has issued several decisions that have extended to minors at least some constitutional protections with respect to the right to

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[16] *Family planning services* are contraceptives and other birth control services, with the exceptions of sterilization and abortion.

[17] In *Griswold* v. *Connecticut* [381 U.S. 479 (1965)], the U.S. Supreme Court held that State regulation of use of contraceptives by married persons invaded "the zone of privacy created by several constitutional guarantees" and struck down as unconstitutional a State statute prohibiting the use of contraceptives by married persons. In *Eisenstadt* v. *Baird* [405 U.S. 438 (1972)], the Court held that unmarried as well as married persons had a right to privacy with respect to contraceptive use.

[18] In *Carey* v. *Population Services International* [431 U.S. 678 (1977)], the Supreme Court specifically held unconstitutional a State statute prohibiting the sale or distribution of contraceptives to minors. The Court indicated that "State restrictions inhibiting privacy rights are valid only if they serve any significant State interest . . . that is not present in the case of an adult."

[19] The Supreme Court ruled in *Roe* v. *Wade* that during the first trimester of pregnancy, a State may require only that the abortion be performed by a licensed physician; that after the first trimester, a State may "regulate the abortion procedure in ways that are reasonably related to maternal health;" and that once the fetus is "viable," a State may "regulate, even proscribe, abortion except where it is necessary in appropriate medical judgment, for the preservation of life or health of the mother" [410 U.S. at 164-65].

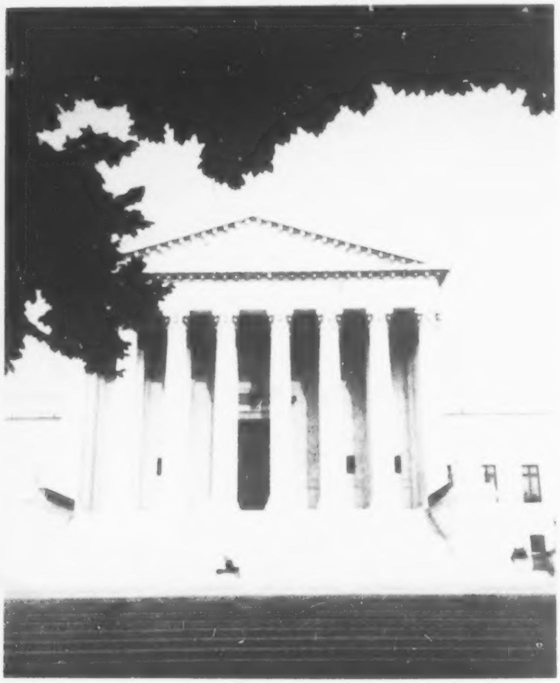

Photo credit: U.S. Congress, Office of Technology Assessment

Laws related to the allocation of authority for decisions about the provision of health services to minors have historically been the province of State legislatures, State courts, and State administrative agencies, but the U.S. Supreme Court decides whether State laws adhere to the requirements of the U.S. Constitution.

have an abortion.[20] The U.S. Supreme Court has not held a parental consent requirement for a minor's abortion to be unconstitutional per se. It has ruled, however, that a minor's parents cannot be given an absolute veto of a minor's decision to undergo an abortion; any parental consent requirement for a minor's abortion must be coupled with the availability of a "judicial bypass" procedure, under which a minor can secure court approval for an abortion if she can demonstrate to the court that she is mature enough to make the abortion decision or that the abortion would be in her best interests. The Court has also indicated that the judicial bypass procedure must ensure a confidential and expeditious proceeding. In the wake of the Supreme Court's *Roe* v. *Wade* decision and related decisions, about one-quarter of the States have enacted statutes requiring parental consent to abortion for minors. Some of these State statutes have been invalidated or are currently being challenged on Federal constitutional grounds, however, so not all of the statutes are currently being enforced.

It is important to emphasize that Federal constitutional law concerning the permissible scope of State regulation of abortion as interpreted by the U.S. Supreme Court is in flux. The Supreme Court's decision in the 1989 case *Webster* v. *Reproductive Health Services* [109 S. Ct. 3040 (1989)] appears to give the States greater leeway in restricting abortions and at the same time casts doubt on the future of *Roe* v. *Wade* and other Supreme Court decisions dealing with abortion. To the extent that *Webster* and future rulings increase States' ability to restrict abortion generally, they may reduce minors' access to abortion—even though the decisions do not directly address the question of parental consent.

Exceptions for Pregnancy-Related Health Services—Over half of the States have statutes specifically authorizing minors to consent to pregnancy-related health services (e.g., testing to determine pregnancy, prenatal care, and delivery services). Since these consent statutes are directed at pregnant minors, they are in effect adolescent consent statutes.

Exceptions for Health Services Related to Drug and/or Alcohol Abuse[21]—All but five States (Alaska, Arkansas, Oregon, Utah, and Wyoming) and the District of Columbia have statutes specifically authorizing minors to consent to drug- and/or alcohol-related health services or to receive such services without parental consent. Two-thirds of the States have statutes covering health services related to both drug and alcohol abuse and dependency; other States have statutes covering health services related to drug abuse or alcohol abuse but not both. The majority of State statutes that allow minors to obtain treatment for drug and alcohol abuse without parental consent do not impose minimum age requirements, although some of them pertain only to minors who have reached a designated age—ranging from 12 to 16 years of age.

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[20] Notable Supreme Court decisions dealing with parental consent to a minor's abortion include *Planned Parenthood of Missouri* v. *Danforth* [428 U.S. 52 (1976)], In *Bellotti* v. *Baird* (Bellotti II) [443 U.S. 622 (1979)], *City of Akron* v. *Akron Center for Reproductive Health, Inc.* [462 U.S. 416 (1973)], and *Planned Parenthood Association* v. *Ashcroft* [462 U.S. 476 (1983)].

[21] For a discussion of health services related to drug and alcohol abuse, see ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II.

State statutes that create an exception to the parental consent requirement with respect to services for drug or alcohol abuse would appear to represent an acknowledgment on the part of State legislatures of the seriousness of drug and alcohol abuse problems among adolescent minors. They would also appear to be the product of a concern on the part of State legislatures that minors may not obtain care related to such abuse if they have to secure parental consent for such care, because "communications" between parents and minors regarding alcohol or drug abuse may "be strained or nonexistent" (81).

Exceptions for Mental Health Services[22]—A little under half of the States have statutes that allow some minors to obtain *outpatient* mental health services without parental consent. These statutes typically impose age restrictions and pertain only to adolescent minors. Underlying these statutes appears to be a legislative realization that a parental consent requirement might deter some adolescent minors who have mental health problems from seeking needed treatment because of a reluctance to reveal such problems to their parents.

Inpatient mental health services for minors present special problems in the area of consent. The involuntary commitment of a person to a mental institution or facility results in the deprivation of that person's liberty, so certain safeguards are in place (e.g., substantive criteria for commitment and procedures pertaining to due process) to ensure that such commitment is necessary. For voluntary commitment, however, such safeguards are not mandated, and as a concomitant of the parental consent requirement for the provision of health services to minors, parents have sometimes been allowed to make a "voluntary commitment" of a minor child to a mental institution or facility, regardless of the minor's desire or need for services.

In *Parham* v. *J.R.* [442 U.S. 584 (1979)], the U.S. Supreme Court rejected the contention that an adversary hearing was required to decide whether a minor may be committed by his or her parents in order to protect the minor, but held that the risk of error in the parental decision to commit a minor to a mental health facility was sufficiently great as to call for an inquiry by a neutral fact finder to determine whether the statutory criteria for admission were met. About two-thirds of the States now have statutes that allow parents to make a voluntary commitment to a mental health facility of a minor child. These statutes vary substantially in the safeguards they provide against inappropriate use of hospitalization or institutionalization to manage "troublesome" minor children who do not have severe mental health problems.[23] According to one analysis, "In general, . . . minors are significantly less able than are adults to resist mental hospitalization sought for them by others" (85).

About half of the States have statutes that authorize minors to apply for admission as an inpatient to a mental institution or facility without parental consent. Most of these statutes impose minimum age limits, the most common being 16 years of age or older. Finally, a few States have statutes that require both the minor's consent *and* a parent's consent for inpatient mental health services.

Confidentiality and Parental Notification Requirements

It has long been accepted that the confidentiality of the relationship between a physician and patient, as well as of the relationship between other types of health care providers and their patients or clients, is essential to a patient's trust in a health care provider and to a patient's willingness to supply information candidly (68). Courts and legislatures have established a physician-patient privilege to protect the confidentiality of communications between physicians and their patients and have established similar privileges to ensure the confidentiality of communications between other types of health care providers and their patients or clients (29). Furthermore, there is a developing case law imposing liability on physicians for unauthorized disclosure of confidential information about their patients (8) (although all health care professionals are required by law to disclose information in situations where there is a strong societal interest in disclosure—e.g., in the reporting of cases of suspected child abuse to the public child welfare authorities (47)).

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[22] Mental health services for adolescents are reviewed in ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II.

[23] Some people are concerned that the rising admission to psychiatric units of private hospitals are indicative of widespread misuse of commitment to control "troublesome" minors (85). See ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II, for further discussion.

By and large, the confidentiality of the relationship between health service providers and minors and the disclosure of confidential information by health service providers to the parents of minors or other third parties are not addressed in case or statutory law. Requirements that parents be notified of a minor's decision to obtain health services or of the minor's actual receipt of health services, however, have in fact become a "legal" issue. In carving out exceptions to the requirement for parental consent to the provision of health services to minors, courts and legislatures have sometimes—though not always—replaced the parental consent requirement with a parental notification requirement.

The justifications for requiring that the parents of minors be notified of the decisions of their minor children to obtain health services are essentially the same as—or at least very similar to—the justifications for requiring that parents consent to health services for minor children. One justification for parental notification requirements is to ensure that parents play an appropriate "guiding role" in counseling their minor children about health care decisions—a role assumed to be needed given the presumed incompetency of minors to make health care decisions based upon minors' assumed lack of decisionmaking capacity.[24] Another major justification is to bolster parental direction and control of their minor children and thereby to maintain the family structure.[25]

Parental Notification Requirements for Health Services Provided to "Emancipated," "Independent," or "Mature" Minors

The prevailing pattern in the many State statutes that authorize "emancipated minors" to obtain health services without parental consent is for these statutes to be silent concerning parental notification; only a few of these statutes contain various kinds of parental notification provisions. The same prevailing pattern is found in States' "independent minor" statutes and "mature minor" statutes.

Parental Notification Requirements for Emergency Health Services

The prevailing pattern in the many State statutes that create an exception to the parental consent requirement in health emergencies is for the statutes to have no provisions concerning parental notification; only a handful of these statutes have some sort of parental notification provisions.

Photo credit: Los Angeles Free Clinic, Project Able

Courts and legislatures seem to regard parental notification requirements as less burdensome for adolescents than parental consent requirements, but it is not clear that adolescents in conflict with their parents make this distinction.

Parental Notification Requirements for Specific Types of Health Services

Many parental notification provisions appear in State statutes that create exceptions to parental consent requirements by allowing minors to consent to health services related to sexual activities, health services for drug and alcohol abuse, or mental health services (see discussion of these exceptions above). Although the legislatures and courts appear to regard the requirement of parental consent as more onerous from the standpoint of an adolescent than the requirement of parental notification, *it is not clear that adolescents distinguish between parental consent and notification requirements*. According to one observer, it is "immaterial to the adolescent just when parents learn (before or after the fact of treatment) or how parents learn (by mandatory consent, by notification, or by inadvertent disclosure through parental reading of the health record)" (43).

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[24] See, for example, *H.L.* v. *Matheson*, 450 U.S. 398 (Burger, J.) (Powell, J. concurring); *H.L.* v. *Matheson* 420-25 (Stevens, J. concurring); and B.D. Hofman, "The Squeal Rule: Statutory Resolution and Constitutional Implications—Burdening the Minor's Right of Privacy" (44).

[25] See, for example, M. Boumil, "Dispensing Birth Control in Public Schools: Do Parents Have a Right To Know?" (23).

Notification Requirements for Health Services Related to Sexual Activities—Parental notification requirements related to health services involving sexual activities pertain to the three major categories of services mentioned earlier: 1) health services related to venereal, sexually transmitted, and infectious diseases and acquired immunodeficiency syndrome (AIDS); 2) family planning services and abortion services; and 3) pregnancy-related health services.

Notification Requirements for Health Services for Venereal, Sexually Transmitted, and Infectious Diseases and AIDS—The many State statutes that authorize minors to obtain testing and treatment for venereal, sexually transmitted, or infectious diseases without parental consent generally *do not* require parental notification. A few States have statutes that specifically state that services for these diseases may be furnished to minors without parental notification; nearly one-third of the States have statutes that give health professionals general discretion to notify parents or discretion to notify parents under certain specified circumstances; nearly two-thirds of the States have statutes that contain no parental notification provisions; and one State has a statute that mandates parental notification under limited conditions.

The relatively small number of State statutes that permit minors to be tested and treated without parental consent for infection with HIV (the virus that causes AIDS) generally do not require parental notification. A few States have statutes with provisions giving health professionals general discretion to notify or discretion to notify parents under specified circumstances; one State has a statute that contains no parental notification provision; and one State has a statute requiring confidentiality unless a minor's HIV test results are positive, in which case parental notification is required.

Notification Requirements for Family Planning Services and Abortion Services—Only a few of the State statutes that permit minors to consent to *family planning services* without parental consent have provisions pertaining to parental notification of the minor's application for receipt of such services, and nearly all of these provisions allow but do not compel parental notification. As of mid-1990, the U.S. Supreme Court had not directly addressed the constitutionality of parental notification requirements that involve parents in a minor's decision about obtaining family planning services.

In 1983, the U.S. Department of Health and Human Services unsuccessfully attempted to promulgate Federal regulations *requiring* that family planning clinics receiving Federal funds under Title X of the Public Health Service Act[26] notify parents of unemancipated minor children when contraceptives were prescribed.[27] These regulations—issued pursuant to a congressional amendment to the authorizing statute for the Title X family planning program that provided that "[t]o the extent practical, entities which receive grants or contracts under this subsection shall encourage family participation in projects assisted under this section" [42 U.S.C. § 300(a) (1982)]—aroused a great deal of controversy and were the subject of litigation in the Federal courts. Ultimately, two Federal courts enjoined the Department from implementing the regulations.[28]

Although the issue of parental notification has also generated a great deal of attention in relation to minors' access to *abortions*, the U.S. Supreme Court has not dealt extensively with parental notification in cases involving abortion services for minors. In the 1981 case *H.L.* v. *Matheson* [450 U.S. 398 (1981)], however, the Supreme Court sustained the constitutionality of a State statute requiring a physician to notify "if possible" the parent of a minor upon whom an abortion is to be performed as applied to a minor living with and dependent on her parents; the Court left open the question of whether the statute would be constitutional as applied to emancipated or mature minors.

In *Hodgson* v. *Minnesota* [110 S.Ct. 2926 (1990)], handed down in June 1990, the Supreme Court struck down as unconstitutional a section of a Minnesota statute requiring that both parents of an unemancipated minor be notified before she undergoes an abortion, except under very limited circumstances. However, the Court upheld the constitutionality of a section of the statute providing for the same two-parent notification requirement with the addition of a "judicial bypass" procedure. In a contemporaneous decision, *Ohio* v. *Akron Center for Reproductive Health* [110 S.Ct. 2972 (1990)], the Court upheld the constitutionality of an Ohio statute making it a crime for a physician or other person to perform an abortion on an unmarried, unemancipated minor unless: 1) there was timely notice to one of the minor's parents, her guardian, or custodian; 2) the minor's parents, guardian, or custodian had consented to the abortion; 3) a juvenile court had issued an order authorizing the minor to consent to the abortion, thereby bypassing parental notification for consent; or 4) judicial inaction under certain circumstances constitutes constructive authorization for the minor to consent.

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[26] For further discussion of the Title X family planning program, see ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II and ch. 19, "The Role of Federal Agencies in Adolescent Health," in this volume.

[27] The regulation provided that 10 days after prescribing a contraceptive drug or device for a minor, the family planning clinic must notify the minor's parent [45 CFR § 59.5(a)(12)(i)(A)].

[28] The Court of Appeals for the Second Circuit held that the 1981 amendment to Title X did not authorize the regulation mandating parental notification [*New York* v. *Heckler*, 719 F.2d 1191 (2d Cir. 1983)]. The Court found that Congress did not intend to require parental notification but merely to encourage parental involvement. The Court of Appeals for the District of Columbia held that the regulation requiring parental notification was inconsistent with congressional intent with respect to Title X [*Planned Parenthood Federation of America* v. *Heckler*, 712 F.2d 650 (D.C. Cir. 1983)].

A little under one-quarter of the States have statutes requiring parental notification of a minor's abortion decision. In the wake of the *Webster* ruling, there has been increased debate as to whether parental notification of abortions involving minors should be required,[29] and the Supreme Court's decisions as to the constitutionality of the two State statutes just mentioned may furnish an impetus for additional State legislative activity aimed at requiring parental notification in the case of a minor's decision to have an abortion.

Notification Requirements for Pregnancy-Related Health Services—The many State statutes that authorize minors to obtain pregnancy-related health services without parental consent generally *do not* require parental notification. One State has a statute that explicitly provides that prenatal care may be furnished without parental notification; somewhat under one-third of the States have statutes that have no provisions regarding parental notification; and about one-fourth of the States have statutes that provide for parental notification at the discretion of health professionals.

Notification Requirements for Health Services Related to Drug and/or Alcohol Abuse—The many State statutes that allow minors to obtain health services for drug and/or alcohol abuse without parental consent exhibit considerable variation when it comes to parental notification provisions—and this variation makes generalizations difficult. Some of these State statutes are silent as to parental notification; some of the statutes require that a minor's drug or alcohol abuse treatment be kept confidential under specified circumstances; some of the statutes leave parental notification up to the discretion of the health professional or to the discretion of the health professional under certain specified circumstances; a few State statutes require parental notification attempts; and a few of the statutes require parental notification or require parental notification under certain specified circumstances.

In 1987, the U.S. Department of Health and Human Services issued a final rule for federally funded alcohol and drug abuse programs that *prohibits* such programs from notifying a minor's parent of the minor's application for treatment without the minor's written consent to notification in States where State law permits minors to obtain alcohol or drug abuse treatment without parental consent [42 CFR, Part 2 § 2.14 (1989)]. This prohibition covers, among other things, the disclosure to a minor's parent of patient identifying information for the purpose of obtaining financial reimbursement; however, "these regulations do not prohibit a program from refusing to provide alcohol or drug abuse treatment until a minor consents to the disclosure necessary to obtain reimbursement. . ." [42 CFR, Part 2 § 2.14 (1989)]. In States where State law requires parental consent to alcohol or drug abuse treatment, the rule states that the fact of a minor's application for treatment may be communicated to the minor's parent only if: a) the minor has given written consent; or b) the minor "lacks the capacity for rational choice" regarding such consent (e.g., because of extreme youth or physical condition) and the minor's "situation poses a substantial threat to the physical well-being of the minor or other person" that may be alleviated by parental notification [42 CFR, Part 2 § 2.14 (1989)].

Notification Requirements for Mental Health Services—The many State statutes under which minors can consent to mental health services or

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[29] See C. Collins, "Abortion Focus Shifting to Teenagers" (30); New York Times, "Kansas Is Urged To Curb Abortion" (70); New York Times, "Virginia Senators Stall Bill To Curb Abortion" (71).

Photo credit: Joe M. Sanders, American Academy of Pediatrics

Laws requiring parental consent and notification in the provision of health services to adolescents do not affect adolescents' access to services unless there are conflicts or potential conflicts between adolescents, their parents, and health care professionals.

receive mental health services without parental consent vary in terms of parental notification requirements. The majority of State statutes that allow minors to consent to *outpatient* mental health services are silent as to parental notification, and the remainder of statutes specify that mental health treatment should be confidential, specify that notification is at the discretion of health professionals, or mandate parental notification under designated limited conditions. The majority of State statutes that allow minors to consent to *inpatient* mental health services similarly do not have parental notification provisions, and the remainder provide for parental notification at the discretion of health professionals, or provide for notification under certain circumstances. Perhaps not surprisingly, inpatient mental health statutes are more likely than outpatient statutes to require or permit parental notification.

The Impact of Law Requiring Parental Consent and Notification on Minors' Access to Health Services

What is the impact of law requiring parental consent to health services for minors or requiring parental notification of the provision (or intended provision) of health services to minors? More specifically, what is the impact of parental consent and notification requirements on minors' access to health services and on minors' utilization of health services?

Several factors affect the impact of legally mandated parental consent and notification requirements on minors' access to and utilization of health services. One factor is *whether—and if so, to what degree—there are actual or potential conflicts between minors, the parents of minors, and health professionals in the making of health care decisions involving the minor.* As noted earlier, laws requiring parental consent and notification do not become critical, or even relevant, unless there are such conflicts. In some cases, the way a health professional presents information to a minor and the minor's parents and what kind of relationship he or she has with them may have a decisive influence on the nature and extent of such conflict. If a health professional has knowledge, skills, and experience regarding the management of potential conflicts, some conflicts may well be avoided (43,77).

On the other hand, some conflicts between minors, their parents, and health professionals over health care decisions affecting the minor are probably unavoidable. There is some evidence that actual or potential conflicts do occur in a significant number of cases involving decisions about the provision of family planning and abortion services to adolescent minors.[30] What is not known, however, is whether—and if so, to what degree—actual or potential conflicts occur in cases involving decisions about *other* health services that minors, particularly adolescent minors, may want or need.

Another factor that affects the impact of legally mandated parental consent or notification requirements for the delivery of health services to minors is whether—and if so, to what degree—health care providers comply with these requirements in providing health services to minors. Laws might be expected to evoke compliance, carrying with them as they do sanctions for violations and constituting as they do a societal declaration that certain conduct is right or wrong. Clearly, however, laws differ in their effectiveness. Noncompliance with parental consent or notification laws on the part of health professionals might occur because the professionals misunderstand or do not know the legal requirements. Noncompliance might also occur because the legal requirements, at least as applied to particular factual situations, are at odds with the ethical standards as expressed in statements by professional organizations of their profession (see box 17-A) or with their personal ethical values and norms. OTA is unaware of any empirical studies and data concerning compliance and noncompliance with legally mandated parental consent or notification requirements that would permit valid conclusions about the extent of compliance and noncompliance among health service providers.

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[30] See, for example, Brief for Petitioners at 16-23 *Hodgson* v. *Minnesota* [853 F.2d 1452 (8th Cir. 1988) (en banc), appeal filed (U.S. Feb. 3, 1989) (No. 88-11257), 110 S.Ct. 400 (1989)].

To the extent that legally mandated parental consent and notification requirements are adhered to by health professionals, the issue arises of whether—and if so, to what degree—such requirements may operate as barriers to adolescents' access to needed health services. As noted earlier, it is not clear that adolescents distinguish between parental consent and notification requirements. With parental consent and notification requirements in place, one possible scenario is that a substantial number of parents of adolescents would frequently and strongly object to the provision to their children of at least some health services—for example, family planning or other services associated with sexual activity, services for substance abuse, and services for mental health problems. A possibly related scenario is that a large number of adolescent minors would be unwilling to reveal to their parents their need for health services—or at least their need for certain services associated with sexual activity, drug or alcohol abuse, or mental health problems—and therefore would delay or be deterred from seeking these services entirely.

Several empirical studies concerning the impact of parental consent and notification requirements indicate that such requirements—at least in the case of family planning and abortion services—do create barriers to adolescents' access to and utilization of services (21,22,25,26,28,78,79,87,88). What cannot be said with certainty, however, is whether the findings of these studies of the impact of parental consent and notification requirements on adolescents' access to family planning and abortion services can be extrapolated to other types of health services.

One other point related to evaluating the impact of parental consent and notification requirements is deserving of mention. Even if the laws in a given jurisdiction do not *require* that a parent consent to health services for a minor and/or that the parent be notified of the provision or intended provision of health services to a minor, *health care providers*—both institutional providers (e.g., hospitals, clinics, and health maintenance organizations) and individual providers—*may as a matter of policy or practice refuse to provide services to minors* without parental consent and/or notification. One of the main reasons that health care providers may refuse to provide services without parental consent is probably financial—i.e., *providers may be concerned that a minor will be unable to pay for services provided and that the minor's parents will not pay for services because they have not consented to or been notified of the*

Photo credit: March of Dimes Birth Defects Foundation

In the case of family planning and abortion services, studies have found that parental consent and notification requirements pose a significant barrier to adolescents' access to and utilization of services. Quite probably, such requirements also pose similar barriers to adolescents' access to other types of services (e.g., mental health treatment, drug abuse treatment, alcohol abuse treatment).

Box 17-A—Professional Ethical Standards Relevant to Consent and Confidentiality

A central principle of medical ethics is that "a physician may not reveal the confidences entrusted to him in the course of medical attendance . . . unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or the community" (9). Many organizations of physicians, nurses, psychologists, social workers, and other professionals engaged in providing health services to adolescents have issued or approved professional ethical standards that similarly stress the importance of maintaining confidentiality between the health professional and the patient or client being served but at the same time acknowledge that legal obligations and the welfare of the individual and the community may take precedence over confidentiality (2-4,6,7,9-16,65-67).

Few of the ethical standards issued or approved by organizations of health professionals speak directly to issues of consent and confidentiality as they arise in the provision of health care to *adolescents*. A conference sponsored by the American Academy of Pediatrics in 1981 sought to address that problem. Conference participants from a variety of disciplines agreed that the following principles should govern consent and confidentiality in adolescent health care:

- With respect to adolescence, there exists an enduring need to balance delicately the relative rights and needs of minors to confidential health services with the relative rights and responsibilities of parents toward their offspring.
- Adolescents should have access to needed health services.
- Adolescents, unless fairly adjudged incompetent, should participate in decisions pertaining to their health.
- The concept of "mature minor" and the capacity of that individual to consent is recognized.
- Even when adolescents seek health care on their own consent, they should be encouraged to involve their parents, unless there is compelling reason not to do so. (In that case, often an alternative adult adviser/relative is appropriate.)
- Chronologic age is not a suitable yardstick to determine an adolescent's maturity and capacity to give informed consent. Development criteria are far more telling, as applied on an individual basis.
- Adolescents generally should be entitled to confidentiality in their own health care, and that presumption should be overridden only by good reason.
- Parental notification should be encouraged but not be made mandatory in the provision of adolescent health care, especially inasmuch as the absence of guaranteed confidentiality could deter many young persons from seeking and receiving necessary services.
- Adolescents should have the same right of access to their health care records as do adults unless there is compelling reason to the contrary.
- Disclosure of health data to third parties, such as health insurers, should only be with parents' informed consent and/or that of adolescents if it pertains to care they have received on their own. As a general rule, adolescents should retain the right to consent to such disclosure with or without parental participation, and even if the adolescent did not originally consent to the health care, unless there is a compelling reason not to.
- Health providers and third-party repositories periodically should review data collected during an individual's minority to reassess its relevance, expunging data no longer needed.
- To protect adolescents, they should be provided with some record as to where their health information was sent, when it was sent, and for what purpose (5).

In 1989, the American College of Obstetricians and Gynecologists (ACOG) issued a policy statement setting forth the most extensive ethical standards pertaining to consent and confidentiality in adolescent health care to date. The statement, which has since been approved by the American Academy of Family Physicians, the American Academy of Pediatrics, the NAACOG (the Organization for Obstetric, Gynecologic, and Neonatal Nurses), and the National Medical Association, provides as follows:

1. Health professionals have an ethical obligation to provide the best possible care and counseling to respond to the needs of their adolescent patients.
2. This obligation includes every reasonable effort to encourage the adolescent to involve parents, whose support can, in many circumstances, increase the potential for dealing with the adolescent's problems on a continuing basis.
3. Parents are frequently in a patient relationship with the same providers as their children or have been exercising decisionmaking responsibility for their children with these providers. At the time providers

establish an independent relationship with adolescents as patients, the providers should make this new relationship clear to parents and adolescents with regard to the following elements:

a. The adolescent will have an opportunity for examination and counseling apart from parents, and the same confidentiality will be preserved between the adolescent patient and the provider as between the parent/adult and the provider.

b. The adolescent must understand under what circumstances (e.g., life-threatening emergency) the provider will abrogate this confidentiality.

c. Parents should be encouraged to work out means to facilitate communication regarding appointments, payment, or other matters consistent with the understanding reached about confidentiality and parental support in this transitional period when the adolescent is moving toward self-responsibility for health care.

4. Providers, parents, and adolescents need to be aware of the nature and effect of laws and regulations in their jurisdictions that introduce further constraints on these relationships. Some of these laws and regulations are unduly restrictive and in need of revision as a matter of public policy. Ultimately, the health risks to the adolescents are so impelling that legal barriers and deference to parental involvement should not stand in the way of needed health care (7).

The ACOG policy statement and American Academy of Pediatrics conference principles encourage parental involvement in adolescent health care decisions but do not endorse the current legal requirements of parental consent and notification. The support of health professionals serving adolescents for that statement and principles indicates that many of these professionals are—at least in theory—more willing than most courts or legislatures have been to grant adolescents autonomy in health care decisionmaking and to afford protection to the confidentiality of the relationship between a provider of health services and an adolescent patient or client. Furthermore, at least one empirical study suggests that health professionals are willing to support these ideas in practice (60).

A question that remains is how helpful existing standards in the form of statements by professional organizations are in resolving the kinds of ethical problems that professionals encounter in providing health services to adolescents. The following situations, compiled by a national authority on adolescent medicine, are illustrative of potential conflicts between interests of the adolescent, the adolescent's parents, and the state (77):

- A 16-year-old boy is discovered to have a malignant bone tumor. Appropriate treatment requires amputation of his leg. His parents consent to the surgery but he refuses. He will accept all other forms of treatment but would "rather die with both legs than survive as a cripple!" Do you operate without the consent of the boy? Do you seek a court order against the wishes of the boy?
- A 17-year-old boy is admitted to the intensive care unit with multiple fractures and disorientation. He was the driver of an automobile involved in a collision in which three passengers were killed. As part of the evaluation of his state of consciousness you determine that his blood alcohol level is well above the legal limits for intoxication. Do you share this information with his family in explanation for his confusion? Do you share this information with the authorities who are investigating this fatal accident?
- A 16-year-old girl is brought to care by her mother who is concerned about her daughter's poor school performance and disruptive behavior. In your private interview with the girl, she confides that she is smoking marijuana a few nights each week. The girl feels that her current problems relate to the unrealistic expectations of her mother regarding performance and behavior. She insists that the confidentiality of her interview be respected and that the information about her drug use not be shared with her mother. Do you tell the mother anyway? What if the mother specifically asks, "Is my daughter using drugs?" The mother requests that a portion of the urine sample collected for routine analysis be sent for drug testing. Do you accede to this request?
- A 15-year-old girl returns with her parents to discuss her recently diagnosed pregnancy. Her parents are certain that the only acceptable course of action is to terminate the pregnancy. The girl is adamant in her refusal to consider an abortion. What do you do?
- A 16-year-old girl is brought for evaluation by her mother because of a complaint of abdominal pain. Physical examination and laboratory evaluation reveal a vaginal discharge secondary to gonorrhea. The girl admits to multiple brief intimate relationships over the past few months. She states that her mother would "kill her" if she found out. You know the family and the mother is a bit of a tyrant with a quick temper. What do you tell the mother?

Continued on next page

Box 17-A—Professional Ethical Standards Relevant to Consent and Confidentiality—Continued

- An 18-year-old homosexual male comes in and requests testing for AIDS. His affect is depressed and upon questioning he admits to frequent suicidal ideation and one prior attempt. He is certain "he would kill himself" if he finds out he has AIDS, but must know the results of his testing because not knowing is "driving him crazy." Do you do HIV testing?
- You are caring for a 17-year-old intravenous drug abuser whom you know to be HIV positive. For the very first time he appears to be sincerely motivated to enter into a drug abuse treatment program. He asks that you complete the required preadmission history and examination form but insists that you make no mention of his HIV status. Do you fill out and sign the form omitting reference to his HIV status?
- A recently married 18-year-old with a past history of homosexual activity is found to be HIV positive. He refuses to inform his bride. He is certain she would leave him. Do you tell her?
- You are caring for a 17-year-old who has AIDS secondary to a transfusion. His 16-year-old girl friend is aware of the diagnosis, but they continue to have unprotected intercourse. She "doesn't care"; she "loves him." Do you inform her parents?

Unfortunately, existing ethical standards by professional organizations would appear to give little concrete guidance and direction to adolescent health service providers in resolving many of these problems. Perhaps the limitation of professional standards in giving guidance in actual situations is inevitable given the sui generis nature of most ethical problems. It is very troublesome, however, given the complex dilemmas that the service providers often encounter in serving adolescents.

provision of services.[31] Another reason may be providers' concern that the effectiveness of the services provided will be reduced by lack of parental involvement or belief that the effectiveness of the services provided will be enhanced by parental involvement.

Minors' Competency To Make Health Care Decisions

As noted at the beginning of this chapter, individuals traditionally have been treated as legally competent or incompetent for purposes of health care decisionmaking on the basis of their age rather than a determination of their actual capacity for decisionmaking. As a general rule, the law presumes that adults are competent to consent to health care and that minors are incompetent. The legal presumption that minors as a class are incompetent to consent to health services rests at least in part on the assumption that minors as a class lack the requisite decisionmaking capacity. The legal presumption that adults are competent is rebuttable under some circumstances upon a factual showing of actual lack of decisionmaking capacity; however, the legal presumption that minors are incompetent is not rebuttable by a factual showing of actual presence of decisionmaking capacity in the absence of legislatively or judicially sanctioned rules permitting such a showing.

The factual validity of assumptions that minors lack the requisite capacity to make health care decisions has been increasingly challenged.[32] Accordingly, the presumption that minors are incompetent to make health care decisions has been increasingly subject to criticism on the ground that it inequitably denies minors in middle or late adolescence—some of whom actually have the requisite decisionmaking capacity—the power to make their own determinations about obtaining health services (82). Since assumptions concerning minors' lack of health care decisionmaking capacity seem largely to reflect the intuition of judges and legislators rather than hard evidence, it is important to identify empirical research bearing upon the validity of these assumptions and to evaluate whether such research supports modification or elimination of the presumption that minors are incompetent to make their own health care decisions.

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[31] If a parent has consented to health services for his or her minor child, the parent is usually financially liable for the services. If a parent has not consented to health services for the minor child, however, the parent is usually not financially liable unless the services are determined to be "necessary." If the parent is not financially liable, the health care provider may attempt to collect from the minor child, but collection may prove difficult because the minor may have the power to disaffirm the contract for services or may have insufficient financial resources to pay for the services. As noted at the beginning of this chapter, one of the rationales for the parental consent requirement seems to be to assure providers of the availability of a payment source for their services.

[32] See, for example, G. Melton, "Children's Consent: A Problem in Law and Social Science" (61).

Empirical research bearing on the competency of minors to make health care decisions was reviewed by OTA's contractors and is discussed below. Before turning to that research, however, it is necessary to examine two definitional issues: first, what constitutes *effective legal consent* to health services; and second, what constitutes *legal competency* to make such consent.

Ambiguities in Legal Definitions of Consent and Competency

What Constitutes Effective Legal Consent to Health Services

As alluded to at the beginning of this chapter, the tort law doctrine of informed consent requires physicians and surgeons to obtain from their patients informed consent for medical treatment or surgery; failure to obtain informed consent may give rise to civil liability.[33]

The informed consent doctrine has been developed in judicial opinions and codified by legislation and does not readily lend itself to a concise summary. Nevertheless, one leading tort law authority has summarized the doctrine as follows:

> The informed consent doctrine is based on principles of individual autonomy, and specifically on the premise that every person has the right to determine what shall be done to his own body. Surgeons and other doctors are thus required to provide their patients with sufficient information to permit the patient himself to make an informed and intelligent decision on whether to submit to a proposed course of treatment or surgical procedure. Such a disclosure should include the nature of the pertinent ailment or condition, the risks of the proposed treatment or procedure, and the risks of any alternative methods of treatment, including the risks of failing to undergo any treatment at all. Thus, although the procedure is skillfully performed, the doctor may nevertheless be liable for an adverse consequence about which the patient was not adequately informed.
>
> In addressing the perplexing question of whether the patient needed to know about a particular undisclosed risk in order to make an informed decision, the courts often speak in terms of the materiality of the risk: the doctor's duty is to disclose all risks which are "material." The extent of this duty to disclose has traditionally been based upon a professional medical standard—whether physicians customarily inform their patients about the type of risk involved, or whether a reasonable physician would make the disclosure in the circumstance. Since the use of a professional standard paternalistically leaves the right of choice to the medical community, in derogation of the patient's right of self-determination, a number of recent cases have defined the duty in terms of the patient's need to know the information—based on whether a reasonable person in the patient's position would attach significance to the information.
>
> In addition to proving the doctor's failure to provide sufficient information, on whatever standard, the plaintiff must also establish a causal link between the nondisclosure and his harm, by proving that he would not have undergone the treatment had he known of the risk of harm that in fact occurred. . . . [Citations omitted] (53).[34]

Rationales for the informed consent doctrine are to promote the patient's autonomy and protect the patient's right of self-determination (64), to protect patients against depersonalized authoritarian medical treatments, and to encourage rational decisionmaking (59). It is important to note that focus of the doctrine as it has been articulated and applied is on the *duty of health professionals to disclose information* to an individual. The focus has not been on the individual's actual understanding of the information disclosed.

What Constitutes Legal Competency To Make Health Care Decisions

The legal concept of competency has a very long history and is central to existing laws governing health care decisionmaking with respect to adolescents. On the one hand, as noted earlier, the well-established legal requirement that parents must *consent* to the provision of health services for their minor children is partially an outgrowth of the presumption that minors are incompetent (which in turn is based on assumptions of their lack of decisionmaking capacity). To some extent, judicial and statutory parental *notification* requirements applied to minors are also derived from this presumption and assumption. On the other hand, "mature minor" and some other exceptions to the parental consent requirement, as discussed earlier in this chapter, represent a rejection of the presumption of minors' incompetence (and underlying assumptions of their lack of decisionmaking capacity) as applied to some minors under certain circumstances.

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[33] To be legally effective, consent to health care services must be both "informed" and also be "voluntary." The concept of voluntariness is not well defined (17).

[34] For discussion of the development of the informed consent doctrine, see P.S. Appelbaum, C.W. Lidz, and A. Meisel, *Informed Consent: Legal Theory and Clinical Practice* (17); for a State-by-State analysis of the application of the informed consent doctrine, see A.J. Rosoff, *Informed Consent: A Guide for Health Care Providers* (73).

Unfortunately, neither the courts nor the legislatures in this country have furnished much guidance as to the content and meaning of competency in the context of health care decisionmaking. The U.S. Supreme Court has most fully articulated its assumptions concerning the minors' lack of health care decisionmaking capacity (which underlie the presumption of minors' incompetency to make health care decisions) in decisions dealing with minors' rights to obtain contraceptives and abortions without parental involvement and in decisions dealing with the civil commitment of minors by parents (see discussion above). A thread that runs through these Supreme Court decisions is the Court's concern that minor children do not possess the intelligence, maturity, and experience that their parents possess. Another thread that runs through these decisions is the Court's concern that minors are not capable of making informed and voluntary decisions. The Court's specific concerns in this regard are that minors may not understand or appreciate the short-or long-term consequences of their decisions, that they may be susceptible to interpersonal pressures in making decisions, and that they may make unwise decisions detrimental to their welfare.

Courts—and, to a lesser extent, legislatures—have probably come closest to enunciating a *standard* for determining the competency of minors to make health care decisions in connection with exceptions to parental consent requirements for "mature" minors (see discussion above). The standard for judging competency in these cases is essentially whether the minor is capable of understanding the nature and consequences of proposed medical or surgical treatment and procedures. Unfortunately, however, this standard for determining a minor's competency provides little real assistance for its application in particular cases.[35]

Recognizing the need to define with more specificity a criterion for determining whether a person, including an older minor, is competent to make health care decisions, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research noted that three general criteria have been used to determine if a patient lacks capacity to make health care decisions: the outcome of the decision, the status or category of the patient, and the patient's functional ability as a decisionmaker.

> The outcome approach—which the Commission expressly rejects—bases a determination of incapacity primarily on the content of a patient's decision. Under this standard, a patient who makes a health care decision that reflects values not widely held or that rejects conventional wisdom about proper health care is found to be incapacitated.
>
> Using the status approach, certain categories of patients have traditionally been deemed incapable of making treatment decisions without regard to their actual capabilities. Some of these categories of patients—such as the unconscious—correspond closely with actual incapacity. But other patients who are presumed to be incapacitated on the basis of their status may actually be capable of making particular health care decisions. Many older children, for example, can make at least some health care decisions, mildly or moderately retarded individuals hold understandable preferences about health care, and the same may be true in varying degrees among psychotic persons.
>
> The third approach to the determination of incapacity focuses on an individual's actual functioning in decisionmaking situations rather than on the individual's status. This approach is particularly germane for children above a certain age variously described as from seven to mid-teens. . . . .
>
> The Commission recommends that determinations of incapacity be guided largely by the functional approach, that individuals not in certain basic categories (such as under the age of 14, grossly retarded, or comatose) should be assumed to possess decisionmaking capacity until they demonstrate otherwise, and that incapacity should be found to exist only when people lack the ability to make decisions that promote their well-being in conform-

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[35] See, for example, G.B. Melton, "Legal Regulation of Abortion, Unintended Effects" (62).

ity with their own previously expressed values and preferences. [Citations omitted] (72).[36]

The failure of courts and legislatures to furnish much guidance as to the content and meaning of competency in terms of health care decisionmaking has had important implications for the strategies adopted in empirical studies of the capacity of minors to make health care decisions. Because courts have not provided operational definitions of legal standards for minimally competent decisionmaking, researchers have been unable to use an operational definition of competency corresponding to the legal definition. Thus, researchers seeking to test the validity of the law's presumption that adults are competent and minors are incompetent to make health care decisions have had to resort to an alternative strategy—namely, comparing decisionmaking by minors to decisionmaking by adults (i.e., individuals age 18 and over). Since adults are presumed by the law to be competent, adults' decisionmaking capabilities implicitly set the standard against which the decisionmaking capabilities of minors are to be judged. If the decisionmaking of minors and adults were found to be indistinguishable, the argument for lowering the age of legally effective consent would be strengthened, although other considerations would have to be taken into account as well. Virtually all of the empirical research on the competency of minors to make health care decisions reviewed by OTA's contractors recognizes that the standard of comparison is the decisionmaking ability of adults.

Empirical Research on Minors' Competency To Make Health Care Decisions

To review the empirical research on the competency of minors to make health care decisions, OTA's contractors selected a core group of seven empirical studies that address the cognitive development of minors and tested whether minors differ from adults in their ability to make health care decisions (1,18,48,49,55,56,86). Those core studies, which are listed in table 17-1, share the following characteristics:

- they involve health care decisionmaking;
- they involve participants whose ages span or overlap the range of 10 to 18 years;
- they involve comparison groups with at least some subjects legally considered adults—i.e., age 18 or over[37] (although no adult participants in the core studies were older than 25 and most were 21 or younger); and
- they appear to be methodologically adequate.

In addition to the core group of studies, a few other studies that lack one or more of the features just mentioned but nevertheless provide insight into decisionmaking by minors were reviewed (40,51,57, 58,76). Some of these other studies address decisionmaking domains not addressed in the core group of studies (e.g., legal decisionmaking); and some of them deal with the effect on decisionmaking of a variable or variables other than age (e.g., the differential vulnerability of minors and adults to social influence of peers, family, or professionals).

Findings of the Core Group of Empirical Studies on the Age-Competence Relationship in Health Care Decisionmaking

The findings of the core group of seven empirical studies on the age-competence relationship in health care decisionmaking reviewed by OTA's contractors are summarized in table 17-1 and discussed in more detail below. *These core studies generally found few differences in health care decisionmaking as a function of age for adolescents as young as 14 or 15 years of age.* It is important to note that most of the core studies did not collect information on decisionmaking by adults older than 25, and most of the core studies did not collect information on decisionmaking by adolescents under age 13 (i.e., ages 10 to 12).

Lewis, 1980—The 1980 study by Lewis compared hypothetical pregnancy decisions for 42 unmarried minors (ages 13 to 17) and young adults (ages 18 to 25) awaiting the results of pregnancy tests in a clinic (55). Those who learned they were pregnant would be faced with the decision whether to have an abortion or deliver a child. All 42

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[36] See also L.H. Roth, A. Meisel, and C.W. Lidz, "Tests of Competence To Consent to Treatment" (74). (The various legal, medical and psychiatric tests of competency being utilized may be categorized as: evidencing a choice, "reasonable" outcome of choice, choice based on "rational" reasons, the ability to understand, and actual understanding.)

[37] As noted previously, this OTA Report focuses on individuals ages 10 through 18. Legally, 18-year-olds are considered adults in all but three States (where the age of majority is 19). In the studies comparing decisionmaking capabilities of adults and minors listed in table 17-1, therefore, 18-year-olds are regarded as adults.

Table 17-1—Summary of Seven Core Empirical Studies of the Age-Competency Relationship in Health Care Decisionmaking

Study[a]	Sample	Decision domain	Influence of age on decisionmaking	
			No differences	Differences found
Lewis, 1980	N = 42 Ages 13-17 v. 18-25 Possibly pregnant, unmarried females; diverse socioeconomic statuses; urban California	Pregnancy: knowledge of law, source of advice, reasons for choice	In knowledge of laws; in number of types of people consulted; in advice expected; in consideration of childrearing ability; in hypothetical advice giving.	The 18- to 25-year-olds were more likely to consult a professional; consider their own ability to care for a child. The 13- to 17-year-olds were more likely to consider impact of a child on their parents; to consider possibility of deformity; and to perceive decision as externally determined.
Lewis, 1981	N = 108 Ages 12-19 (grades 7-8, 10 and 12) Middle to upper socioeconomic status; 87% expected to attend college; San Francisco	Cosmetic surgery, choice of custodial parent, research: on acne medication, on "mind"	In consulting with peers or parents; in revising attitudes in light of new information.	With increasing age, there was increasing probability of mentioning risks, future consequences, and desirability of consulting an independent specialist, as well as caution against persons with vested interests.
Weithorn and Campbell, 1982	N = 96 Ages 9, 14, 18, 21 Half male, half female; white; middle socioeconomic status; younger groups, Long Island; older groups, Washington, DC	Choice of treatment alternatives for diabetes, epilepsy, enuresis, depression; risks, benefits, etc.	In expression of a decision preference or choice of treatments among 14-, 18-, 21-year-olds; in reasons for choice (except as noted); in factual understanding and appreciation of problems/consequences (except as noted).	The 9-year-olds differed from other groups on treatment choices for depression; they were more likely to choose inpatient treatment. In reasons for choices, 9-year-olds differed from other groups; 14-year-olds differed on epilepsy. In factual understanding of the condition and appreciation of the consequences, 9-year-olds differed from all others.
Belter and Grisso, 1984	N = 60 Ages 9, 15, 21 All males; predominantly white; middle-class; average to above average IQ	Recognizing and protecting against violations of patients' rights by a professional	In recognition or protection of patients' rights between 15- and 21-year-olds who were briefed about such rights.	The 9-year-olds showed less recognition of patients' rights violations and failed to protect their own rights more often than the other two groups.
Kaser-Boyd et al., 1985	N = 62 Ages 10-13 v. 14-20 Behaviorally disordered, emotionally disturbed, learning disabled; some with, without prior therapy experience; 70% middle socioeconomic status, 20% low-mid, 10% low; mostly white, 16 nonwhite; 67% male; probably LA.	Psychological treatment; risks, benefits	In identifying risks [Author's note: ns were too small in some instances to complete chi-sq]; in 8 benefit dimensions.	Nonsignificant trend for 10- to 13-year-olds to say did not know if risks existed. In benefits, 14- to 20-year-olds thought psychotherapy helped you learn new things. The 14- to 20-year-olds used more abstract concepts in describing benefits.

Table 17-1—Summary of Seven Core Empirical Studies of the Age-Competency Relationship in Health Care Decisionmaking—Continued

			Influence of age on decisionmaking	
Study[a]	Sample	Decision domain	No differences	Differences found
Kaser-Boyd et al., 1986	N = 75 Ages 10-19 Adolescents with mild to severe learning and behavioral problems; mostly upper middle socioeconomic status, low to mid socioeconomic status; mostly white, 14 nonwhite; probably LA.	Psychological treatment; risks, benefits, and irrelevant considerations	In distinguishing risks, benefits, and irrelevant considerations; in treatment decision vignettes.	None
Ambuel, 1989	N = 75 Ages 13-21 All females; diverse racial, economic, and religious backgrounds	Broad range of knowledge, affect, decision conflict around unplanned pregnancy	In cognitive or volitional competence (except among females ages 13 to 15 who did not consider abortion an alternative).	Females ages 13 to 15 who did not consider abortion scored lower on the measure of volitional competence and most measures of cognitive competence.

[a] Full citations are listed at the end of this chapter.

SOURCE: Office of Technology Assessment, 1991, adapted from J. Gittler, M. Quigley-Rick, and M.J. Saks, "Adolescent Health Care Decisionmaking: The Law and Public Policy," prepared under contract to the Carnegie Council on Adolescent Development for the Office of Technology Assessment, U.S. Congress, Washington, DC, February 1990.

participants were asked to respond to a hypothetical question seeking advice for a person in that situation.

In terms of the decision as to whether to have a child, this study found that the minors and young adults did not differ from each other in terms of knowledge of relevant laws, number or types of people consulted, the advice anticipated from those consulted, or considerations of childrearing ability in giving advice to another person.

On the other hand, the young adults in the study were more likely than the minors to want to consult an independent professional and more likely to consider their own childrearing abilities in deciding whether or not to have a child themselves. The minors were more likely to consider the impact of their child on their own parents and gave more weight to the likelihood of possible deformity of their baby. Furthermore, the minors tended to perceive the decision as being more externally determined than as being within their own power to make. (This perception may simply reflect the minors' life experience in other domains.)

Lewis, 1981—The 1981 study by Lewis asked students ages 12 to 19 (grades 7-8, 10, and 12) what advice they would give peers who were faced with a variety of choices: cosmetic surgery, choice of custodial parent, a research trial involving acne medication, and research on "the mind" (56). This study found no age-related differences in advice the participants said they would give regarding consultation with peers or parents and found no age-related differences in participants' revisions of attitudes in the light of new information.

On the other hand, this study found that with increasing age from 12 to 19, there was an increasing tendency among participants to mention risks, future consequences, and the desirability of consulting an independent specialist (i.e., a specialist without vested interests in the choice made), and there was an increasing tendency to express caution about the advice of persons with vested interests in the choice made.

Weithorn and Campbell, 1982—The 1982 study by Weithorn and Campbell presented hypothetical treatment dilemmas involving four health problems (diabetes, epilepsy, enuresis, and depression) to participants ages 9, 14, 18, and 21 and asked participants what decisions they would make and the reasons for those decisions (86).

This study found that groups of participants ages 14, 18, and 21 did not differ in their decisions or reasons for decisions. Moreover, the decisions of these participants did not differ from those recommended by health professionals for the problems in question. Groups of participants ages 14, 18, and 21 also did not differ from each other on tests of factual understanding of the health problems or appreciation of the consequences associated with various options.

The group of 9-year-olds, this study found, did differ in many ways from the older groups. The 9-year-olds were more likely than the older groups to select inpatient treatment for depression. Indeed, the study found an overall trend for younger participants to be accepting of inpatient treatment and older participants to reject it. The 9-year-olds also differed from the older groups in the reasons for their choices of treatment, in factual understanding of the conditions, and in appreciation of consequences.

Belter and Grisso, 1984—The 1984 study by Belter and Grisso studied the ability of 60 middle-class males ages 9, 15, and 21 to recognize a violation of their rights as patients in a simulated counseling session and to take steps to assert and protect their rights against violations by the professional (18). The research procedure involved half the participants at each age level receiving briefings on the rights of patients (e.g., the rights to refuse treatment, to know the reason for referral, to withhold information, to refuse to allow tape recording of the session, and the rights of confidentiality and access to records). In a subsequent session, participants observed a videotaped counseling session and were asked at various points whether or not a right was being violated and, if so, what they would do to protect the right.

The Belter and Grisso study found that 15-year-olds did not differ from 21-year-olds in their scores on the recognition or protection of rights or in the benefit they gained from the briefings about patients' rights. On the other hand, this study found that 9-year-olds showed significantly lower recognition of or asserted protection of rights than did the 15- or 21-year-olds, who did not differ from each other.

Kaser-Boyd et al., 1985—The 1985 study by Kaser-Boyd et al. compared behaviorally disordered, emotionally disturbed, and learning disabled individuals ages 10 to 13 to those ages 14 to 20 in their ability to assess risks and benefits of psychological treatment (48).

This study found that the 10- to 13-year-olds did not differ from the 14- to 20-year-olds in the identification of risks or evaluation of eight benefit dimensions. A serious problem noted by the authors, however, is that in some of these comparisons, the numbers were too small to permit a significance test to be performed. In terms of differences in decisionmaking as a function of age, this study found that participants ages 14 to 20 identified more potential benefits from psychotherapy and expressed the perceived benefits in more abstract terms than participants ages 10 to 13.

Kaser-Boyd et al., 1986—The 1986 study by Kaser-Boyd et al. asked 75 adolescents ages 10 to 19 with mild to severe learning and behavior problems to distinguish among risk and benefit factors, as well as irrelevant considerations, with respect to a hypothetical decision to accept or refuse psychotherapy (49). One might regard the decisionmaking ability of a group of adolescents with problems such as these as immediately suspect, but in fact a group such as this may be the right group of adolescents to be testing, because it is adolescents with problems such as theirs who might actually be asked to decide whether to accept psychotherapy. Although this study does provide comparisons in decisionmaking among younger and older study participants up to 19 years of age, it does not provide comparisons between subjects with and subjects without the problems mentioned.

In any event, this study found no differences in decisionmaking as a function of age. Participants ranging in age from 10 to 19 years of age showed no differences in distinguishing risks, benefits, and irrelevant considerations, or in the psychological treatment decisions they made.

Ambuel, 1989—The 1989 study by Ambuel collected and analyzed data from 75 socioeconomically diverse females ages 13 to 21 who suspected an unplanned pregnancy and were visiting a medical clinic for a pregnancy test (1). This study is noteworthy for combining a real-world setting in which research participants faced a potentially serious and stressful decision with extensive and careful measurement of attitudes, affect, and cognition.

The study found that—apart from females ages 13 to 15 who said they excluded abortion as an option—participants showed no age-related differences in three measures of cognitive competence (thoroughness of consideration of consequences, number of reasons considered, and quality of the process and content of reasoning about pregnancy) or in a measure of "volitional competence."

Females ages 13 to 15 who did not consider abortion as an option (but no other groups of minors, categorized either by age or attitude toward abortion) had significantly lower scores than adults age 21 and under on every measure of competence except one measure of cognitive competence (the number of reasons considered). This difference suggests that females ages 13 to 15 who regard abortion as a possibility have cognitive and volitional competencies similar to or indistinguishable from those of young adult females, whereas females age 13 and above whose competencies are lower have ruled abortion out and are therefore not likely to seek an abortion anyway.

Findings of Other Studies on the Age-Competence Relationship in Health Care Decisionmaking

The finding of several studies that are not part of the core group discussed above provide some additional insight concerning age-related similarities and differences in health decisionmaking.

Lewis et al., 1977—A 1977 study by Lewis et al. systematically observed the behavior of elementary school children ages 5 to 12 in an innovative program in two Los Angeles schools (58). That program allowed children to decide when a health problem required the attention of the school nurse, to sign themselves out of class to see the nurse, and to choose among treatment options presented to them by the nurse. In short, the program allowed the children the same freedom as adults in making their own health care choices, and the children's choices had real consequences for treatment.

The authors of this study found that children in their school's self-activated health program made sensible (even in adult terms) use of their power to choose. It is interesting to note that the elementary school children in this study are below the age at which we would have any theoretical reason based on developmental psychology to expect equivalence between child and adult decisionmaking.

Lewis et al., 1978—A 1978 study by Lewis et al. invited 213 elementary school children ages 6 to 9, grouped in their classes, to become informed about swine flu vaccine trials and to decide whether or not to volunteer to participate (57). If a child did volunteer, the consent of the child's parents was sought, and if granted, the child did participate in the vaccine trial. Thus, the child's decision had potential real consequences.

This study found very few age-related differences in the ability of classes of children to elicit information about the flu and the vaccine and about potential risks and benefits of participation in a vaccine trial, although one class of 6-year-olds did not elicit all the relevant information it could have. It is important to note that this study really measured group ability—rather than individual ability—to elicit information critical to making the decision to participate in medical research. If, as seems likely, there is significant variation in decisionmaking capacity among individuals *within* age groups, then measuring group ability would tend to minimize differences *between* age groups. In other words, assuming that the percentage of individuals who could think of all the questions to ask increases with age, then any of these groups might *as groups* be able to ask all the right questions and appear equally capable, while in fact important developmental changes were occurring over time (as larger and larger percentages of children in older classes would individually be able to ask the appropriate questions). The basic question before us pertains to the competence of minors as individuals and the information-seeking of individuals that is more typical of the informed consent process in our institutions. Still, it is striking that even in a group of 6-year-olds, there are enough group members that in all but one class all the relevant information was elicited by the children.

Kazdin, 1986—A 1986 study by Kazdin had parents and their severely disturbed children rate the acceptability of different kinds and settings of mental health treatment (51).[38] This study found that parents rated both outpatient treatment and hospitalization as more acceptable than their children did. The parents rated hospitalization higher than outpatient treatment; the children rated them in the reverse order. Furthermore, the strength of treatment was positively correlated with acceptability for parents and negatively correlated for children. According to Kazdin, these differences may very well reflect differences in the meaning of the treatments for parents (e.g., relief) and children (e.g., abandonment).

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[38] Special problems in the area of consent to mental health services were discussed earlier in this chapter. For a discussion of various mental health treatment settings available to adolescents, see ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II.

Grisso, 1981—An important note of caution is raised by a study that addresses not medical decisionmaking by minors but legal decisionmaking—Grisso's 1981 study of juveniles interrogated by police, with particular attention to the decisionmaking of these youths in asserting or waiving their legal rights (39). This study reminds us that minors making decisions in different contexts and different subsets of minors may show important differences in decisionmaking as compared with adults.

This study found that 42 percent of arrested adults chose not to answer police questions but that fewer than 10 percent of arrested juveniles asserted their right to remain silent—and virtually none of the arrested juveniles under age 15 refused to answer police questions.[39] As a group, juveniles under age 15 showed little comprehension of the *Miranda* warning[40]—so little comprehension in fact that their decisions to assert or waive those rights had little meaning. Furthermore, as many as half of the juveniles ages 15 to 16 who had IQs below 80 or who were black or in lower socioeconomic groups also showed little comprehension of their legal rights and the consequences of asserting or waiving their rights. This study found that white juveniles who had greater contact with juvenile courts and police evinced improved understanding of *Miranda* rights, but black juveniles who had such contact evinced poorer understanding. Greater contact with police and courts did, however, lead to greater understanding of the different roles of judges, lawyers, and police.[41]

Findings of Studies on How Variables Other Than Age Affect Adolescents' Health Care Decisionmaking

Variables other than age have important effects on decisionmaking, and several studies involving some of these other variables in the context of health decisionmaking by minors are described below. The studies reviewed here do not permit any definitive conclusions about how variables such as gender, socioeconomic status, race and ethnicity, intellectual skills, experience, condition severity, pressure from peers or family, or skill training affect decisionmaking by minors. They do, however, point to areas in which the gathering of additional data about minors' decisionmaking capacity would probably be useful.

Gender—Only one core study reviewed by OTA's contractors specifically examined effects of gender on decisionmaking. That study, the 1982 study by Weithorn and Campbell, used equal numbers of male and female participants and found no gender differences in decisionmaking in hypothetical treatment situations (86). Two other studies that examined the effect of gender and were reviewed by OTA's contractors were the 1977 and 1978 studies by Lewis et al. The 1977 study by Lewis et al. reported that the patterns of utilization of health services by elementary school boys and girls (ages 5 to 12) participating in their school's self-activated health program paralleled the utilization patterns of adults—i.e., girls made more use of the services than boys (58). The 1978 study by Lewis et al. reported that elementary school boys and girls ages 6 to 9 did not differ in the questions they asked after being invited to volunteer for swine flu trials, but reported both that boys volunteered less often than girls and that girls more often than boys found themselves unable to make a choice about volunteering.

Socioeconomic Status—None of the core studies reviewed by OTA's contractors examined the effect of socioeconomic status on decisionmaking, but decisionmaking by minors from different socioeconomic groups was compared in one of the other studies they reviewed. That study, the 1977 Lewis et al. study, found that the poorer elementary school children (ages 5 to 12) in their school's self-activated health program made more visits to the school health service than the more affluent children (58). Furthermore, the poorer children saw their health as more in the control of physicians, while the more affluent children saw their health as being more influenced by forces that they themselves could control. None of the other studies OTA's contractors reviewed had enough minors from lower socioeconomic strata to allow conclusions about possible differences in decisionmaking related to socioeconomic status.[42]

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[39] The U.S. Supreme Court has found juveniles to be competent to make their own decisions in this context and has held such waiver of constitutional rights by minors to be valid [*Fare* v. *Michael C.*, 442 U.S. 707 (1979)].

[40] The *Miranda* warning is the standard warning given to apprise criminal suspects of their constitutional rights in regard to custodial interrogation by police—they have the right not to answer any questions and the right to the advice and assistance of an attorney.

[41] For a discussion of adolescents in the juvenile justice system, see ch. 13, "Delinquency: Prevention and Services," in Vol. II.

Race and Ethnicity—Only one of the core studies OTA's contractors reviewed reported on the effect of race or ethnicity on decisionmaking by adolescents. That study, the 1986 Kaser-Boyd et al. study among adolescents with mild to severe learning and behavior problems, reported that white, non-Hispanic adolescents obtained higher scores on the psychological treatment decision vignettes than other participants; but only 14 of the 75 subjects in this study were black or Hispanic (49). The 1977 Lewis et al. study reported that as white elementary school children gained experience in their self-activated health program, they increasingly saw themselves as the decisionmakers, but that the same shift did not occur for the black or Hispanic children (58).

Intellectual Skills—Only one of the core studies OTA's contractors reviewed, the 1986 study by Kaser-Boyd et al., compared participants with different intelligence or a comparable measure of intellectual ability (49). This study found, unsurprisingly, that participants with poor reading comprehension scored less well on the decision tasks. A point made earlier in this discussion was that there seems to be considerable variation in decisionmaking ability of individuals *within* particular age groups. This within-group variation could be due to a variable that is more important to the quality of decisionmaking than age. Intelligence or reading comprehension may very well be that variable, but few data on this topic have been collected.

Experience—Only two of the core studies OTA's contractors reviewed examined the effect of experience on decisionmaking. The 1986 study by Kaser-Boyd et al. found surprisingly that participants with learning and behavioral problems who had had experience with psychotherapy obtained lower scores on the psychological treatment decision vignettes than participants without such experience (49). The researchers advanced several hypotheses to account for this finding. The 1985 study by Kaser-Boyd et al. found that participants with learning, behavioral, and emotional problems who had experience with psychotherapy were more likely than participants who had no experience to assert that psychotherapy had low risks and that participants who were currently referred to therapy saw somewhat more benefits to psychotherapy than participants who were not referred (48).

No other studies of which OTA is aware make comparisons among experienced and inexperienced decisionmakers. One would expect decisionmakers experienced with the decision domain to show some differences from those who are new to the decision domain. Presumably, one advantage that older—especially considerably older—decisionmakers have is experience with the decision task, and presumably some decisions benefit more from such experience than others. More research on this topic would probably be useful.

Condition Severity—Only one of the core studies OTA's contractors reviewed examined the effect of condition severity on competence to decide. This study, the 1986 study by Kaser-Boyd et al., found that participants not currently referred for psychological treatment and participants with moderate behavior problems scored higher on the psychological treatment decision vignettes than participants currently referred for psychological treatment and participants with severe behavior problems, respectively (49).

Two of the other core studies provide a partial answer to the question of whether the severity of a condition that does not impair a decisionmaker's intellectual functioning affects decisionmaking, the 1982 study by Weithorn and Campbell (86) and the 1981 study by Lewis (56). These two studies, which presented to participants several different treatment dilemmas varying in seriousness, reported no systematic differences in decisionmaking as a function of the seriousness of the condition.

Social Influence From Peers, Parents, or Professionals—One issue that often is raised, but seldom studied with care, is the ability of minors to make independent decisions not unduly influenced by peers, parents, or professionals. As far as one can tell, the issue of minors' ability to make decisions without undue influence from peers, parents, or professionals has not even benefited from a thoughtful conceptual analysis of the questions that need to be asked. When is a rejection of information from and about others evidence of independent judgment, and when is it a sign of irrationality? When is sensitivity to the ideas and conduct of others thoughtful open-mindedness, and when is it conformity? Does the tendency toward conformity vary with the context? These and many other questions remain to be answered.

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[42] For a further discussion of issues pertaining to the delivery of health and related services to adolescents living in poverty, as well as adolescents in specific cultural subgroups, see ch. 18, "Issues in the Delivery of Services to Selected Groups of Adolescents," in this volume.

None of the core studies OTA's contractors reviewed examined the relationship between age and conformity to social influence in decisionmaking. Available research on the general relationship of age and conformity to social influence suggests the relationship between age and conformity to social influence is complex. The available research shows inconsistent findings, which may be reconciled by positing that conformity to social influence decreases from ages 7 to 11, then increases from ages 11 to 13, and then begins to decrease after that.[43] A 1988 study by Scherer and Reppucci examined the effects of parental pressure on hypothetical health decisions by adolescents ages 14 and 15 and found that these adolescents yielded greatly to parental pressure (76). The Scherer and Repucci study found that the more consequential the health problem and invasive the treatment choices, the less the 14- and 15-year-olds yielded to parental pressure; the more socially sensitive the condition, the more these adolescents yielded to parental pressure.

Surely the amount of social conformity people exhibit varies widely with the social situation and setting as well as with the individual. In fact, it is at least conceivable that developmental effects on social conformity may actually be overshadowed by situational variables. On the other hand, there may be complex situation-by-development interactions. Studies to examine that possibility have yet to be done.

Skill Training—Only one of the core studies OTA's contractors reviewed examined the effect of skill training on competence to decide. In the 1984 Belter and Grisso study, half the participants at each age level received briefings on patient rights and half did not. This amounts to specific training in one aspect of decisionmaking by patients (18). Unsurprisingly, participants who received briefings showed significantly higher recognition and protection scores than participants who did not. The 15- and 21-year-olds both derived significant benefit from the briefing, but the 9-year-olds did not derive any benefit. With the briefings, the 15-year-olds performed indistinguishably from the 21-year-olds in the recognition and protection of their rights as patients.

None of the other core studies OTA's contractors reviewed involved special efforts to teach decisionmaking skills to minors. Some additional research has addressed the question of whether decisionmaking skills can be taught. For example, a 1988 study by Weinstein has prepared children for psychotherapy by using videotaped modeling (84), and a 1986 study by Hammes and Petersen has shown that sixth grade children can be taught resistance to persuasion and thereby taught to make more independent decisions (41). These studies suggest that even if minors *were* found to lack adult-level competence to consent—which in general they have not been—it might be possible to prepare minors to make decisions that reflect a heightened level of competence.

Implications for Public Policy of Empirical Research on Minors' Competence

The studies that form the core of OTA's review on the age-competence relationship in health care decisionmaking, though not great in number, do provide at least some empirical support for the idea that minors as a class—especially minors age 14 or 15 through age 17—have the same capacity to make health care decisions as young adults. *These empirical studies, therefore, challenge the traditional and implicit assumption of the law that minors as a class are unable to make health care decisions as well as adults.* Furthermore, the studies' findings on this point are consistent with a huge body of research on cognitive development generally.[44]

Are the empirical studies reviewed in this chapter sufficient to establish that adolescents as a group, ages 14 or 15 and above, are competent to consent to their own health care? Probably not. Beyond being

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[43] See P. Costanzo and M. Shaw, "Conformity as a Function of Age Level" (32); and B. Bishop and L. Beckman, "Developmental Conformity" (20).

[44] See D. Elkind, "Conceptual Orientation Shifts in Children and Adolescents" (34); J. Flavell, *The Developmental Psychology of Jean Piaget* (36) and "An Analysis of Cognitive-Developmental Sequences" (37); B. Inhelder and J. Piaget, *The Growth of Logical Thinking From Childhood to Adolescence* (46); D.P. Keating, "Thinking Processes in Adolescence" (52); G.B. Melton, G.P. Koocher, and M.J. Saks, *Children's Competence To Consent* (63); and E.D. Neimark and N. Lewis, "Development of Logical Problem Solving: A One-Year Retest" (69).

Photo credit: U.S. Congress, Office of Technology Assessment

Available empirical research challenges the traditional and implicit assumption of the law that minors as a class are unable to make health care decisions as well as adults.

rather few in number, *the studies reviewed leave gaps in the knowledge ideally needed for the formulation of public policy* pertaining to adolescents' involvement in health care decisionmaking. One limitation of the available studies is that most of them did not examine minors' decisionmaking performance in situations sufficiently real and stressful to see what effects such situations may have on their decisionmaking performance (although the few that did examine this found the same pattern of results as the other studies). Another limitation of the available studies is that they generally compared minors' decisionmaking with the decisionmaking of very young adults rather than with that of adults of various ages. Still another limitation of available studies is that they leave open several important questions about the effects exerted on minors' decisionmaking by factors such as socioeconomic status, ethnicity, social influence, skill training, and experience, and how these might interact with the age-competence relationship found in the generally white middle-class groups studied. It is difficult to know how well one may generalize from the groups studied to the groups not studied.

Two basic responses can be made to the limitations of existing studies of minors' health care decisionmaking capabilities. One would be to carry out studies designed to generate more complete data. The other would be to make judgments as to whether the pattern of findings of existing studies is firm enough to expect them to carry over into untested areas. *Whatever is done, it is important to bear in mind that there is considerable variation among individual adolescents.* Some of the empirical studies reviewed for this chapter *note* the great variation of performance within age groups, but they do not go beyond that. Because of individual variation in decisionmaking capacity among adolescents, some adolescents ages 14 and older do not, in fact, have the requisite capacity to make health care decisions. Even if the average minor of any given age group can make health care decisions as well as the average adult, if the variability is much greater among the minors than it is among adults, then a large absolute number of minors might fall below whatever the standard of competence is.

The problem of individual variation in decisionmaking capacity within an age group can be dealt with in various ways. One way would be for public policymakers to require individualized determinations of competency by courts or even by health professionals. Unfortunately, however, an approach based on individualized determinations would open the door to discriminatory and arbitrary determinations unless there were tests of decisionmaking capacity that were reliable and valid and that could be administered easily—and it is doubtful that there are such tests.[45] Moreover, individualized determinations can be quite expensive in terms of resources.

Another way of dealing with the problem of individual variation in decisionmaking capacity would be for public policymakers to establish a rebuttable legal presumption of competence based on chronological age that could be used by courts to make individualized determinations of competence

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[45] Some observers suggest that not one of the usual tests of competence relied on by the law and health professionals—evidencing a choice, reasonableness of outcome of choice, "rational" reasons, ability to understand, actual understanding—is or can ever be used consistently and that changing circumstances and considerations modify the tests that the law or clinicians apply (74).

(31).[46] Thus, for example, public policymakers could establish a legal presumption that any minor age 14 or above is competent to make health care decisions, but could also allow for the use of evidence of an individual's inability to make such decisions to rebut that presumption.[47]

Finally, it must be noted that considerations of minors' health care decisionmaking capacity have not been the sole determinant of the degree of freedom minors have been granted with respect to obtaining health services on their own. As pointed out earlier in this chapter, the presumption that minors are incompetent to make decisions about health care based on assumptions about minors' lack of health care decisionmaking capacity is only one of several rationales—albeit a major rationale—for parental consent and notification requirements. It also must be noted that only some of the recognized exceptions to parental consent and notification requirements are based on a rejection of this legal presumption and underlying assumptions. *In short, the capacity of a minor to make health care decisions may be a necessary but not a sufficient condition for allowing a minor to obtain health services on his or her own. Conversely, the lack of capacity on the part of a minor to make health care decisions may not preclude allowing the minor to obtain health services without parental permission.*

Conclusions and Policy Implications

This chapter began by asking how the law should allocate authority for making decisions about an adolescent's health care among the adolescent, the adolescent's parents, health professionals, and the state. It is important to emphasize that the way in which the law allocates adolescent health care decisionmaking authority does not become critical, or even very relevant, unless the adolescent and one or another of the parties just mentioned are in conflict. As noted earlier, however, potential or actual decisionmaking conflicts can and do sometimes occur. In the case of family planning and abortion services and possibly other types of health services that may be needed or wanted by adolescents, parental consent and notification requirements may sometimes pose barriers to access.

The ultimate responsibility for deciding how the law should allocate authority for making decisions about an adolescent's health care rests with public policymakers—legislators, judges, and administrators of public programs. If public policymakers are to formulate appropriate public policy pertaining to the allocation of authority for adolescent health care decisionmaking, they must balance the interests of adolescents, parents, health care providers, and the state.[48] Balancing these interests is no easy task, especially when the balancing has to be done in a political environment in which policymakers must rely on value judgments about which there is no consensus. It is at least possible, however, that an analysis of the interests of the various parties involved can serve as a conceptual framework for the development of clearer, more rational, and more consistent policies. Such an analysis is presented in box 17-B.

Laws related to the allocation of authority for decisions about the provision of health services to minors—individuals under age 18 in 47 States and the District of Columbia, and under age 19 in 3 States—have historically been the province of State legislatures, State courts, and State administrative agencies. As noted in this chapter, existing State laws governing parental consent and notification for different types of health services vary widely from State to State, and the laws of a particular State often vary with respect to different types of services or situations. For the most part, therefore, existing State laws do not furnish clear and consistent answers to the question of how authority for minors' health care decisionmaking is allocated.

Given the array of laws and regulations described in this chapter, many adolescents—and perhaps even providers—are probably uncertain about how these laws and regulations pertain to them as individuals. The involvement of the U.S. Supreme Court and lower Federal courts in the allocation of authority for decisions about family planning and abortion services through their power to interpret the

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[46] See F.E. Zimring, *The Changing Legal World of Adolescence* (90).

[47] See President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions, Volume 1: Report* (72).

[48] See R. Bennett, "Allocation of Child Medical Care Decision-Making Authority: A Suggested Interest Analysis" (19); L.S. Ewald, "Medical Decision-Making for Children: An Analysis of Competing Interests" (35); M.S. Wald, "Children's Rights: A Framework for Analysis" (82); Harvard Law Review, "Developments in the Law—The Constitution and the Family" (42); and F.E. Zimring, *The Changing Legal World of Adolescence* (90).

Box 17-B—A Conceptual Framework To Aid Public Policymakers in Formulating Policy Related to the Allocation of Authority for Adolescent Health Care Decisionmaking

A conceptual framework to aid public policymakers in formulating policy related to the allocation of authority for adolescent health care decisionmaking can be supplied by analyzing the interests of the parties who may be involved in such decisionmaking—namely, the adolescent, the adolescent's parents, the health care providers, and the state. The essential issue to be considered in such an analysis is: Does the state have an interest or interests derived from the interests of the adolescent, the adolescent's parents, or health care providers—or does the state have an independent interest—that would justify a particular allocation of authority for adolescent health care decisionmaking via statutes, judicial decisions, or administrative regulations?

Interests of the Adolescent and the State—An adolescent has obvious interests in protecting his or her own life and in maintaining good physical and mental health—interests that translate into an interest in timely access to needed health services. The state, under its parens patriae power, also has an interest in protecting the life and health of the adolescent and thus also has an interest in ensuring the adolescent's access to needed health services. The nature and extent of the adolescent's interest—and by extension the state's interest—in the adolescent's access to health services varies, depending on the type of service and circumstances. Clearly, the interest is greatest in the case of health services that are needed to preserve life (e.g., emergency medical services for a seriously injured or suicidal adolescent) and less in the case of health services that may be viewed as desirable but are not necessary to preserve or even to achieve or maintain health (e.g., cosmetic surgery). In situations where the adolescent's life or health may be at stake, the adolescent's interest in access to services should be paramount in any balancing of interests to arrive at an appropriate allocation of the authority to make decisions concerning the provision of health services to adolescents.

Given the interests of the adolescent and the state in ensuring that the adolescent has access to needed health services, an issue that arises is whether—and if so, to what degree—legally mandated parental consent and/or notification requirements create barriers to adolescents' access to services. Several empirical studies have found that such requirements do create barriers to adolescents' access to and utilization of family planning and abortion services (21,22,25,26,28,78,79,87,88); the applicability of the findings of these studies to other types of services, however, remains unclear. If policymakers are considering the advisability of allowing adolescents to make their own health care decisions, a central concern becomes the competency of adolescents to make appropriate determinations as to their need for services. Some empirical studies, which are reviewed in this chapter, suggest that adolescents ages 14 or 15 and above have the same capacity to make health care decisions as young adults. It is important to bear in mind, however, that these studies have a number of limitations. Furthermore, adolescents within these age groups exhibit individual variation in decisionmaking capacity, and this variation itself has implications for public policy.

Interests of the Adolescent's Parents and the State—Parents and their minor children typically have affectional and other ties, and the parents of most adolescents are likely to have an interest in ensuring that decisions about the provision of health services for their adolescent child will benefit him or her. In some cases, however, an identity of interest between an adolescent and the adolescent's parents cannot be assumed; nor can it be assumed that the parents will always act in the adolescent's best interests in health care decisions affecting the adolescent. Parents have responsibility for the care, support, and rearing of their minor children, and the parents of an adolescent may have an interest in maintaining their authority over the adolescent. The parents also may have a more generalized interest in protecting their family's autonomy and privacy and in promoting their family's stability and cohesiveness.

The state may or may not have an interest in reinforcing parental authority. The state certainly has an interest in having the parents continue to assume responsibility for their adolescent child, however, and if parental authority is reduced, parents may be less willing to assume this responsibility. The state also has an interest in protecting family autonomy and privacy, which are widely valued in American society, but the protection of family autonomy and privacy is not necessarily the same as reinforcing parental authority. The state also has an interest in maintaining family cohesiveness and stability, but this is not necessarily the same as reinforcing parental authority.

Interests of Health Care Providers—The interests of health care providers are seldom discussed or even mentioned in discussions concerning the allocation of authority for adolescent health care decisionmaking. Certainly, however, health care providers can be said to have an interest in providing services to adolescents that

Continued on next page

Box 17-B—A Conceptual Framework To Aid Public Policymakers in Formulating Policy Related to the Allocation of Authority for Adolescent Health Care Decisionmaking—Continued

are consistent with their professional ethics (e.g., standards pertaining to confidentiality) and consistent with accepted professional practices. Providers have an interest in being able to receive compensation for services they provide. Providers also have a more narrow, but nonetheless significant interest, in clear and consistent laws to enable them to avoid unintentional violation of these laws. It is not clear, however, whether or to what degree the state has an interest in promoting or furthering these interests of health care providers.

Independent Interests of the State—Although, to some extent, the state's interests may be derived from and substantially the same as those of the adolescent, the adolescent's parents, and health care providers, the state also has its own independent interests. Thus, the state has a clear independent interest in ensuring that adolescents are tested and treated for sexually transmitted diseases to prevent the spread of those diseases and thereby protect its citizens from these diseases. To the extent that adolescent childbearing results in increased public expenditures for health and human service programs that serve families started when the parents were adolescents (e.g., public programs such as the Medicaid program, the Aid to Families With Dependent Children program, and the Food Stamp Program) and to the extent that adolescent childbearing is associated with negative health, educational, economic, and social consequences for these families,[1] the state may also have an independent interest in ensuring access of adolescents to family planning services and abortion services.

Interests of the Various Parties Depending on the Types of Health Services Involved—The interests of the adolescent, the adolescent's parents, the state, and health care providers may well differ depending on the types of health services involved—and the way the interests are balanced may well differ depending on the types of services involved. Thus, analyzing the interests of the parties concerned may lead to rules regarding the proper allocation of authority for adolescent health care decisionmaking that vary for different types of services. What this means for policymakers is that while one set of rules may appropriately govern the allocation of decisionmaking authority for general medical care, another set of rules may appropriately govern the allocation of decisionmaking authority for family planning services, another set of rules may govern the allocation of this authority for mental health services, and still another set of rules may govern the allocation of this authority for substance abuse treatment and counseling.

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[1] Various studies have different findings considering the consequences of adolescent childbearing (38,54,80,89). For a further discussion of this topic, see ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

provisions of the U.S. Constitution may very well add to their uncertainties. One way of reducing adolescents' uncertainties, apart from moving laws toward greater uniformity, would be to incorporate information about the legal aspects of access to health services for adolescents in health education courses offered to adolescents in a State. Such information would give adolescents the information they need to make choices about whether or not to seek care.

Responsibility for allocating authority for health care decisionmaking now rests primarily with the State courts and legislatures and Federal courts. If it chose to, however, the U.S. Congress could play a greater role in formulating public policies pertaining to the allocation of authority for adolescent health care decisionmaking. At least in theory, Congress may enact legislation that would have the effect of establishing particular substantive policies in this area at the State and local level.[49]

One way for Congress to take on a larger role in formulating public policies pertaining to the allocation of authority for adolescent health care decisionmaking would be to enact legislation conditioning States' receipt of Federal funds for specified purposes on the States' having statutes or administrative rules and regulations that incorporate particular substantive policies with respect to health care decisionmaking for and by adolescents. To OTA's knowledge, this approach has not been used by Congress in this realm to date.

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[49] As noted earlier, the U.S. Supreme Court is the final arbiter of what State laws are permissible and impermissible under the U.S. Constitution.

An alternative way for Congress to expand its role would be to enact legislation that requires federally funded programs that support the provision of health services for adolescents to adopt particular substantive policies with respect to the allocation of authority for adolescent health care decisionmaking. Congress authorizes and appropriates funds for a variety of programs that provide reimbursement or grants for adolescent health services—for example,

- the Medicaid program authorized under Title XIX of the Social Security Act,
- the maternal and child health services block grant programs authorized under Title V of the Social Security Act,
- the family planning services and research program authorized under Title X of the Public Health Service Act, and
- the alcohol, drug abuse, and mental health services block grant program authorized under Title XIX of the Public Health Service Act.[50]

The Federal laws authorizing and appropriating funds for these programs and the regulations and rules issued by the agencies administering these programs at the Federal level generally do not deal directly with questions of whether adolescents must have parental consent to participate in the programs, whether parents must be notified of adolescents' participation in the programs, or whether health care records and communications between program service providers and adolescents are confidential vis-à-vis their parents.[51] In the absence of explicit directives from Congress or Federal agencies, the administrators of federally funded programs are free—so long as they remain within the parameters imposed by State law and Federal constitutional law—to establish their own policies regarding parental consent and notification requirements and the confidentiality of records and communications involving minors.

If Congress were to legislate in the area of parental consent and notification and confidentiality of communications involving adolescents, it presumably would move laws governing matters such as parental consent and notification toward greater uniformity and coherence. Assuming for the sake of argument that greater uniformity and coherence is desirable, there remains the issue of what substantive policies Congress should adopt. That is a political judgment—some people would undoubtedly support requiring or encouraging parental involvement in decisions concerning health services for adolescents and others would support giving adolescents a substantial measure of autonomy in such decisions. To help guide policymakers in decisions governing the allocation of authority for health care decisionmaking, further empirical research on the decisionmaking capabilities of adolescents and factors that may influence these capabilities (e.g., age, prior experience, situational factors, intelligence) would probably be useful.

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[50] Some of these Federal programs are discussed in other chapters of this report. Medicaid, for example, is discussed in ch. 16, "Financial Access to Health Services." The Title X family planning program is discussed in Vol. II in ch. 10, "Pregnancy and Parenting: Prevention and Services." The maternal and child health services block grant program is discussed to some extent in ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services." The alcohol, drug abuse, and mental health services block grant program is discussed in ch. 11, "Mental Health Problems: Prevention and Services," and ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services." A number of these programs are also discussed in ch. 19, "The Role of Federal Agencies in Adolescent Health," in this volume.

[51] There have been some exceptions, for example, the previously discussed final rule issued by the U.S. Department of Health and Human Services in 1987, which prohibits federally funded alcohol or drug abuse programs from notifying a minor's parent of the minor's application for treatment without the minor's consent but only in States where State law permits minors to obtain alcohol or drug treatment without parental consent [42 CFR, Part 2 2.14 (1989)].

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Chapter 18

ISSUES IN THE DELIVERY OF SERVICES TO SELECTED GROUPS OF ADOLESCENTS

Introduction

OTA's analysis of a wide variety of health problems experienced by U.S. adolescents suggests that the incidence and prevalence of many health problems is greater among some groups of adolescents than others.[1] There is also evidence that U.S. adolescents' access to health services is far from uniform. As discussed elsewhere in this report, for example, many adolescents in poor and near-poor families are unable to obtain adequate health care because they do not have health insurance.[2]

This chapter focuses on three broad groups of adolescents and discusses some of the socioeconomic and cultural factors that may affect their health and access to health and related services. The three broad groups of adolescents are as follows:

- adolescents living in poverty,
- racial and ethnic minority adolescents, and
- adolescents living in rural areas.[3]

Without trying to be comprehensive, the chapter identifies some of the special health issues for adolescents who are poor, members of racial or ethnic minorities, or residents of rural areas. It also discusses issues in the delivery of health and related services to these groups of adolescents. Finally, it describes Federal programs pertaining to poor adolescents, racial and ethnic minority adolescents, and adolescents living in rural areas.

It is important to note that the analysis in this chapter is severely limited by a lack of information. In general, systematically collected and analyzed information on socioeconomic and cultural factors important to the appropriate and effective delivery of health services is scarce. Where adolescents are concerned, the problem is even worse.

Adolescents Living in Poverty: Issues in the Delivery of Health and Related Services

In 1988, more than 8 million U.S. adolescents lived in a poor or near-poor family (see figure 18-1). Poor and near-poor are terms defined in relation to the Federal poverty level, a cash income level which varies with family size and the age of family members. Poor families are families whose income falls below the Federal poverty level. Near-poor families are families whose income falls between 100 and 149 percent of the poverty level.

According to data from the March 1989 Current Population Survey, 26.7 percent of U.S. adolescents in 1988 lived in poor or near-poor families (see figure 18-2). About 17 percent of U.S. adolescents age 10 through 18 in 1988 lived in families with incomes below the Federal poverty level, and nearly 10 percent more lived in families with incomes between 100 and 149 percent of the Federal poverty level (106). This means that about 8.27 million of the 31 million U.S. adolescents in 1988 lived in poor or near-poor families—about 5.3 million in poor families and about 3.0 million in near-poor families.[4]

The health and other effects of growing up poor or near-poor are complex and not well understood (154). Because poverty is often associated with low educational level, substandard living conditions, an inadequate social-support network, unemployment, poor nutrition, risk-promoting lifestyle, and diminished access to health care, children growing up in poor or near-poor families probably confront more risk factors and benefit from fewer protective and

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[1] OTA's analysis of selected health problems experienced by U.S. adolescents is presented in chs. 5 through 14 in Vol. II of this Report. For a summary, see app. B, "Burden of Health Problems Among U.S. Adolescents," in this volume.

[2] It is well established that health insurance coverage and ability to pay may determine when or whether a person in this country seeks health care services (125,177). For further discussion of the financial barriers to access confronted by U.S. adolescents, see ch. 16, "Financial Access to Health Services," in this volume.

[3] Clearly, some adolescents fall into more than one of these groups. The rationale for discussing the groups separately is to identify the unique contribution of socioeconomic status, race and ethnicity, and rural residence to health and the delivery and receipt of health and related services.

[4] This calculation is based on the July 1, 1988, civilian population (211).

Photo credit: Mark Charette, Washington, DC

Systematically collected and analyzed information on socioeconomic and cultural factors important to the appropriate and effective delivery of health services to U.S. adolescents is scarce.

supportive factors than their more advantaged peers.[5] Some observers have theorized, however, that ''poverty acts through the prism of culture'' (84a). In other words, cultural traditions, values, beliefs, and practices can either diminish or accentuate poverty's negative effects. For the most part, systematic

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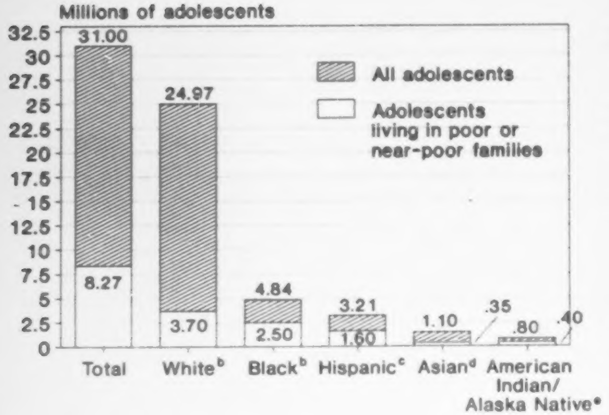
[5] The idea that there is, in addition, a ''culture of poverty'' (121,145) has been controversial (74,93,273). In the 1960s, Lewis argued that poverty is perpetuated because the children of low-income parents are socialized into a value system and set of behaviors that reduces their motivation to succeed in the labor market (121). This thesis aroused controversy because it was seen as blaming the victims of poverty for their own fate. The structural explanation (i.e., that persistent poverty in individual families and certain communities can be explained by such factors as the structure of the welfare system, the economic structure of low-paid jobs, and the location of jobs) has been a major alternative to the culture of poverty in explaining the persistence of poverty (74,93). Wilson, among others, has recognized a relationship between certain aspects of economic change (specifically, the loss of manufacturing jobs in central cities) and the set of behaviors, attitudes, and social perceptions of the impoverished communities particularly affected by these aspects of change (273,273a). In this process, captured by the term ''concentration effects'' (273a), ''neighborhoods that have few legitimate employment opportunities, inadequate job information networks, and poor schools not only give rise to weak labor force attachment but also raise the likelihood that people will turn to illegal or deviant activities for income, thereby further weakening their attachment to the legitimate labor market. A jobless family in such a neighborhood is influenced by the behavior, beliefs, orientations, and social perceptions of other disadvantaged families disproportionately concentrated in the neighborhood'' (73a). These attitudes, beliefs and behaviors affect behaviors related to the workforce and to poverty (e.g., less investment in formal education leads to less ability to obtain a job in the growing service sector of the economy; the lack of marriageable [i.e., employed] males is a factor in out-of-wedlock pregnancies and births). Wilson has limited discussion of concentration effects to the so-called ''underclass'' living in ''urban ghettos,'' in which an impoverished urban ghetto is a census tract in which at least 40 percent of families live below the Federal poverty level (273). Thus, any effects of of poverty on behaviors and values would apply only to a relatively narrow band of poor families (165a). A full exploration of the varying definitions of the urban underclass (13,71,78,93,273,275) and other explanations of the persistence of poverty in selected groups is beyond the scope of this Report. Interested readers are referred to the recent volume edited by Jencks and Peterson for much of the latest thinking on these issues, including chapters on the impact of living in an urban underclass neighborhood on out-of-wedlock adolescent pregnancy (93).

Figure 18-1—Number of U.S. Adolescents Ages 10 to 18 and Number Living in Poor or Near-Poor[a] Families, by Race/Ethnicity, 1988[b]



[a] Poor and near-poor are terms defined in relation to the Federal poverty level, a cash income level which varies with family size and the age of family members. Poor families are families with incomes below the Federal poverty level. Near-poor families are families with incomes from 100 to 149 percent of the Federal poverty level.

[b] This figure shows the approximate number of U.S. adolescents and adolescents living in poor or near-poor families. The population estimates for white and black adolescents are slight overcounts because they include Hispanics, who are also shown separately.

[c] Persons of Hispanic origin may be of any race.

[d] Asian/Pacific Islander includes Filipinos, Chinese, Vietnamese, Koreans, Japanese, Asian-Indians, and "others." The Census Bureau is unable to calculate the number of Asian and Pacific Islanders who are ages 10 through 18 for periods beyond 1980. OTA's rough estimate that there are approximately 1.100 million Asian and Pacific Islanders ages 10 to 18 is made by applying the estimated proportion of Asian and Pacific Islanders who were ages 10 to 18 in 1980 (15.9 percent, derived by taking 9/17ths of the proportion of the Asian and Pacific Islander population who were under 18 in 1980 (30.2 percent)) to the estimated total population of Asian and Pacific Islanders as of July 1, 1989. Better estimates of the 10- to 18-year-old Asian and Pacific Islander population of the United States will be available from 1990 census statistics.

[e] Because of the small number of American Indians and Alaska Natives sampled for the Current Population Survey (CPS), and various limitations of the survey design, the poverty estimates for this group have a large standard error (that is, they may be unreliable). The proportion of adolescents in families with incomes less than 150 percent of poverty could be between 41 and 61 percent (108). However, the high rate of poverty among American Indians and Alaska Natives found through the CPS is consistent with estimates from other sources (199).

SOURCE: Office of Technology Assessment, 1991, based on data from the following sources: **Adolescent population counts:** U.S. Department of Commerce, Bureau of the Census, *U.S. Population Estimates, by Age, Sex, Race, and Hispanic Origin: 1989* Current Population Reports, Series P-25, No. 1057, by F.W. Hollmann (Washington, DC: U.S. Government Printing Office, March 1990); S. Sue and N. Zane, "Health and Related Services for Asian American Adolescents," contract paper prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, November 1989; F. Hollmann, Demographer, Bureau of the Census, U.S. Department of Commerce, personal communication cited in F. Butterfield, "Asians Spread Across a Land, and Help Change It," *New York Times*, Sunday, Feb. 24, 1991, p. 22. **Number of adolescents living in poor or near-poor families:** R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

investigations into whether and how variations in socioeconomic status cause differences in health-related behaviors and attitudes have not focused on adolescents (but see 103). Findings concerning the beliefs and behaviors that characterize the average adults in a population may or may not be applicable to the adolescent children of those adults.

Overview of the Number of Adolescents Living in Poverty

Official estimates of the number of people living in poverty in the United States are available from the Bureau of the Census within the U.S. Department of Commerce.[6] The Bureau of the Census conducts a census of the entire U.S. population every 10 years. The 1980 census included data on sex, race, and marital status from the entire enumerated population and more detailed information on income, education, housing, and other topics from a 20-percent sample of the population (238a). The Bureau of the Census also conducts the Current Population Survey, a monthly household survey of a sample of the civilian noninstitutionalized population, to obtain estimates of characteristics of the labor force, the population as a whole, and various subgroups of the population.[7] Annual data on the number and characteristics of people living in poverty, based on income during the previous year, are obtained in the March supplement to the Current Population Survey (150,210).

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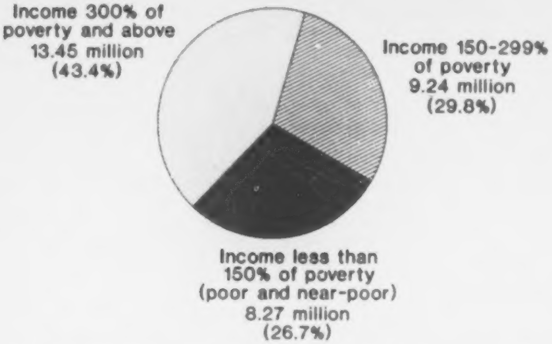
[6] The official government definition of poverty is based on cash income levels for families of different sizes. It was established in the mid-1960s and has not been modified substantially since then (150). Responsibility for changing poverty concepts and definitions rests with the Office of Management and Budget. The definition of poverty has been the subject of numerous congressional hearings and reports (150,198). It is beyond the scope of this report to address the questions that have been raised.

[7] As a household survey of the civilian noninstitutionalized population, the Current Population Survey does not include individuals in institutions (e.g., correctional institutions, detention homes, and training schools for juvenile delinquent youths, homes for dependent and neglected children, homes and schools for the mentally or physically handicapped, or homes for unwed mothers).

Figure 18-2—Socioeconomic Status of U.S. Adolescents Ages 10 to 18, by Family Income as a Percent of the Federal Poverty Level, 1988[a]



[a] Family income is expressed in relation to the Federal poverty level. The Federal poverty level is based on cash income levels for families of different sizes. In 1988, the Federal poverty level was $9,431 for a family of three.

SOURCE: Office of Technology Assessment 1991, based on R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

As shown in figure 18-3, the risk of being poor or near-poor for U.S. adolescents is greatly related to family composition. Adolescents living in mother-headed families without fathers and adolescents on their own are at much greater risk of being poor or near-poor than adolescents living with both parents or their father only (13,106). In 1988, nearly two-thirds of the adolescents who lived with their mother only and two-thirds of the adolescents living with neither parent (or married and living with their parents[8]) lived in families with incomes that fell below 150 percent of the poverty level. That same year, about one-fourth of the adolescents in father-headed families without mothers were in families with incomes below 150 percent of the Federal poverty level. Adolescents living in two-parent families are at the lowest risk of being poor or near-poor; in 1988, about 15 percent of the adolescents living with both parents were in families with incomes below 150 percent of the poverty level.

Family composition affects not only the risk of being poor or near-poor but the dynamics of poverty. Available research on the dynamics of income and poverty indicates that the presence of two parents in a family offers children substantial (though not absolute) protection from sustained poverty (154). Poverty among two-parent families fluctuates widely from year to year and is highly dependent on wages and other income (including Aid to Families With Dependent Children (AFDC)) (154). In contrast, poverty among female-headed families without fathers reflects the vulnerability of having only one parent, usually a mother who is a low-wage earner, as the sole source of economic support (154). Female adolescents who bear children out of wedlock are at particularly great risk of living in poverty.[9]

Data from the March 1989 Current Population Survey indicate that certain groups of racial and ethnic minority adolescents are far more likely than white, non-Hispanic adolescents to be living in families with incomes at or near the Federal poverty level. As shown in figure 18-4, about half of Hispanic adolescents, half of black, non-Hispanic adolescents, half of American Indian and Alaska Native adolescents, and one-third of Asian adolescents in the United States lived in poor or near-poor families in 1988 (106). That same year, less than one-fifth of white, non-Hispanic adolescents lived in poor or near-poor families.

Data from the March 1989 Current Population Survey indicate that some parts of the country have a higher percentage of adolescents living in poor or near-poor families than others. The South[10] has a higher percentage of adolescents who live in poor or near-poor families than the West[11] or North[12]: 31.7 percent of adolescents living in the South, 26.4 percent of adolescents living in the West, and 22.9

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[8] When adolescents are married, even if they are living with their parents, they are usually considered to be a separate family for purposes of the Current Population Survey.

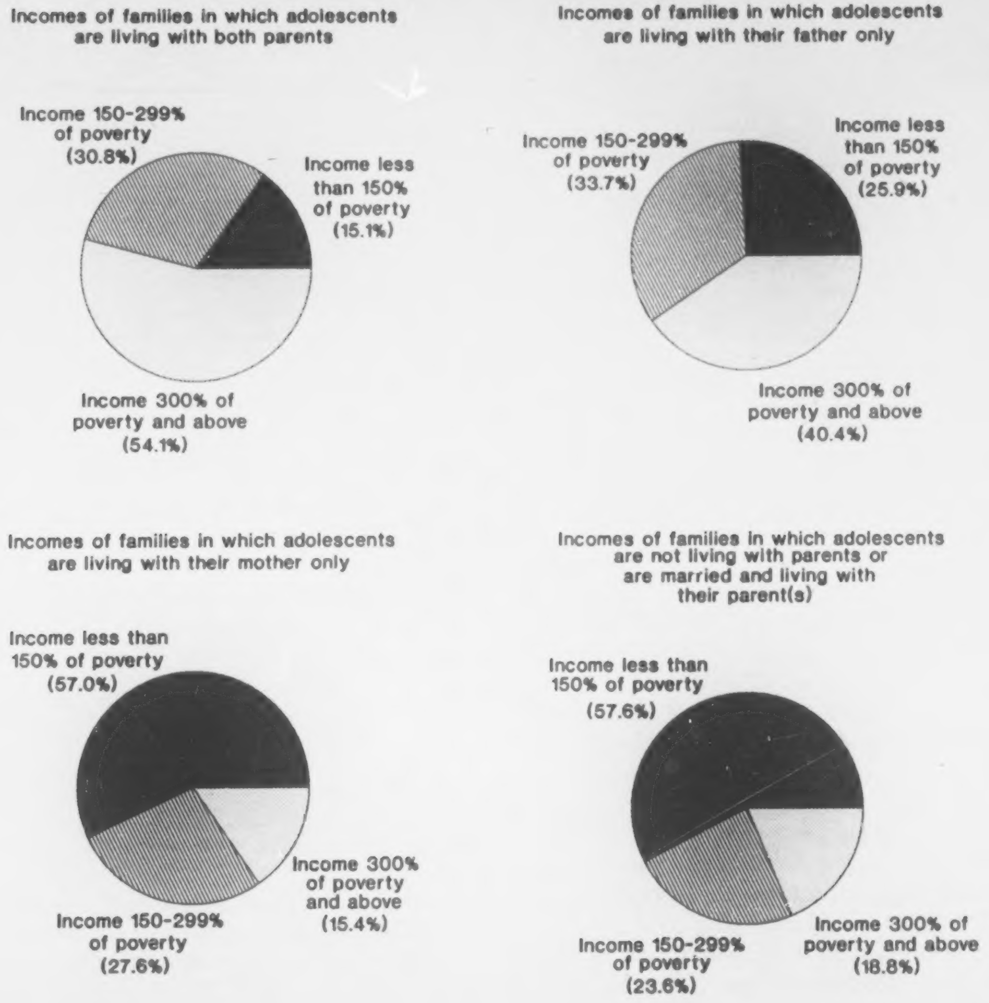
[9] As discussed in ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II, about 65 percent of the approximately 500,000 births to U.S. adolescents in 1988 were out-of-wedlock births (240).

[10] The South includes Alabama, Arkansas, Delaware, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia (107).

[11] The West includes Alaska, Arizona, California, Colorado, Idaho, Hawaii, Montana, New Mexico, Oregon, Nevada, Utah, Washington, and Wyoming (107).

[12] The North includes Connecticut, Illinois, Indiana, Iowa, Kansas, Maine, Massachusetts, Michigan, Minnesota, Missouri, New Hampshire, New Jersey, New York, North Dakota, Nebraska, Ohio, Pennsylvania, Rhode Island, South Dakota, Vermont, and Wisconsin (107).

Figure 18-3—Family Incomes as a Percent of the Federal Poverty Level by U.S. Adolescents' Living Arrangements, 1988[a]



Incomes of families in which adolescents are living with both parents

Incomes of families in which adolescents are living with their father only

Incomes of families in which adolescents are living with their mother only

Incomes of families in which adolescents are not living with parents or are married and living with their parent(s)

NOTE: Figures may not add to 100 percent because of rounding error.

[a] Family income is expressed in relation to the Federal poverty level. In 1988, the Federal poverty level was $9,431 for a family of three.

SOURCE: Office of Technology Assessment, 1991, based on R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

percent of adolescents living in the North live in poor or near-poor families (107).[13] It is important to note that these comparisons are based on the official definition of poverty, which does not take into account variations in the cost of living across regions or across residential areas (i.e., urban, suburban, rural) within regions. Differences in the cost of living in different areas can be quite substantial.

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[13] Data from Midwestern States are not reported as a separate group because of the low numbers of adolescents sampled from Midwestern States; data from these States are reported as part of other regions to increase the reliability of the data (107).

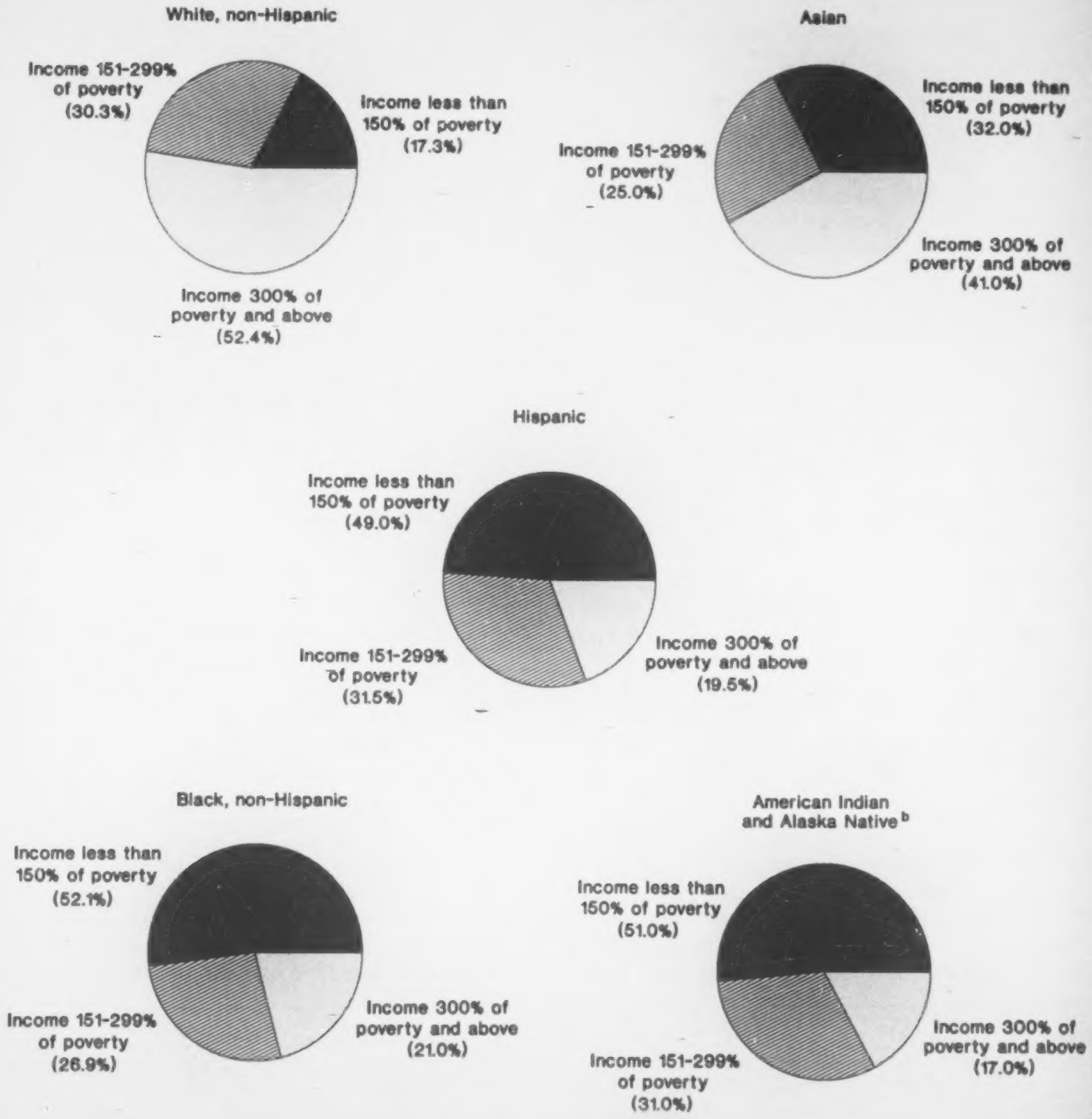

Figure 18-4—Family Incomes as a Percent of the Federal Poverty Level by U.S. Adolescents' Race/Ethnicity, 1988[a]

[a] Family income is expressed in relation to the Federal poverty level. In 1988, the Federal poverty level was $9,431 for a family of three.

[b] Because of the small number of American Indians and Alaska Natives sampled for the Current Population Survey and various limitations of the survey design, the estimates for this group may be unreliable. The proportion with incomes less than 150 percent of poverty could be between 41 to 61 percent (108). However, the high rate of poverty among American Indians and Alaska Natives found through the Current Population Survey is consistent with estimates from other sources (204).

SOURCE: Office of Technology Assessment, 1991, based on R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1989 Current Population Survey public use files, 1990.

Thus, the impact of living in a family whose income falls below the Federal poverty level may differ depending on where one lives.

Health Status of Poor Adolescents

Limitations of Data and Research on the Health of Poor Adolescents

Existing data on the health status of poor adolescents and research on the health effects of poverty have a number of significant limitations. As discussed elsewhere in this report, there is no regular monitoring of U.S. adolescents' health, and information on the health status of U.S. adolescents is often not available.[14] National data on the health status of U.S. adolescents by income level are practically nonexistent.

Data on births, deaths, various indicators of health status, and the utilization of health resources are collected on an ongoing basis by the National Center for Health Statistics in the U.S. Department of Health and Human Services (DHHS). Much of the data collected by the National Center for Health Statistics is not analyzed in terms of income level.[15] Thus, for example, the major Federal report on health indicators in the United States—*Health, United States*—tabulates mortality and most morbidity statistics by age, sex, and race but not by income or other factors indicative of socioeconomic status (156,238a).

One of the few national surveys sponsored by the National Center for Health Statistics that does collect morbidity data by family income is the National Health Interview Survey. The National Health Interview Survey uses personal household interviews to obtain information from a sample of the civilian noninstitutionalized population on personal and demographic characteristics and various health topics (238a). This survey has a number of limitations. As a household survey, it does not include individuals who are homeless or in institutions. For individuals under age 17, information is collected from a proxy respondent, typically a parent or guardian.

The prevailing stereotype of poverty is as an inner city phenomenon, and much of the research on poor people has focused on poor people living in urban areas. Thus, it has often overlooked poor people in rural or suburban areas. In fact, a substantial percentage of poor families with children live in rural areas (30 percent in 1987) or suburban areas (28 percent in 1987) (13). Urban areas tend to have high concentrations of racial and ethnic minority poor people. Thus, much research on the poor has focused disproportionately on people from racial and ethnic minorities. There have been few attempts by researchers to examine poverty's unique impact on adolescents' physical or mental health status, apart from the effects of such factors as family structure, race and ethnicity, and place of residence.

Another problem is that many researchers rely on impressionistic criteria, such as the apparent socioeconomic characteristics of neighborhoods, for determining adolescents' socioeconomic status instead of using multiple criteria including family income levels (146). Adolescents themselves often do not know enough about the details of their parents' employment to permit accurate assessment of their family's economic status.

Finally, it should be noted that much of the research on adolescents living in poverty has focused on the "failures" (e.g., individuals who drop out of school, individuals who exhibit emotional or behavioral problems, individuals who remain dependent on welfare) rather than the successes. These "failures," however, are not representative of all poor adolescents.[16] While the deficit model can

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[14] Data on adolescent health are not collected in any single place, and for many important problems (e.g., nonfatal accidents, sexually transmitted diseases, mental health problems, delinquency), there are no reliable sources of national data. The problems with available information on adolescent health are summarized in app. C, "Issues Related to the Lack of Information About Adolescent Health and Health and Related Services," in Vol. I. Sources and limitations of national data sources on specific aspects of adolescents' health are discussed in each chapter in Vol. II.

[15] The National Health Examination Survey conducted from 1966 to 1970 used a variety of direct physical examinations and clinical and laboratory tests, to obtain information on the measures, including health status of a representative national sample of U.S. adolescents ages 12 to 17. This survey did obtain information on family income, but data from that survey are now over 20 years old. The National Health and Nutrition Examination Survey (NHANES) was initiated as a successor to the National Health Examination Survey in 1971. NHANES III, currently underway, will include questions related to income, but the sample of 3,200 adolescents ages 12 to 19 (56) may be too small to allow meaningful comparisons by income level.

[16] Many children who grow up in welfare-dependent families, for example, do not become welfare-dependent themselves as adults. One study found that 42 percent of black females and 27 percent of white females growing up in highly welfare-dependent families—i.e., defined as families who relied on welfare for at least 25 percent of average total family income in the years between the time the child was between the ages of 10 and 17—did not receive any welfare between the ages of 24 and 30 (196). Only 19 percent of black daughters and 26 percent of white daughters in highly welfare-dependent families in this 1984 analysis became highly welfare-dependent themselves (196).

Box 18-A—Research on Resilient Children and Adolescents

It is well established that some children from impoverished homes or neighborhoods, dysfunctional families, or other adverse circumstances grow up to become mentally and socially healthy adults. Such individuals have sometimes been called "resilient" or "invulnerable" (59,126,268).

Although there has been little longitudinal research tracking children and adolescents from disadvantaged homes and neighborhoods and comparing their long-term outcomes with outcomes among individuals from nondisadvantaged homes, the research that has been conducted generally suggests that two important variables for helping children overcome adverse circumstances are having access to supportive individuals and networks and having personal characteristics that enable one to draw upon this support (e.g., social competence, greater intelligence).

A 30-year longitudinal study of children born on the Hawaiian island of Kauai in 1955 identified 30 percent of the children as high risk because they had experienced four or more selected risk factors—e.g., experiencing moderate to severe perinatal stress, growing up in chronic poverty, having parents with no more than an eighth grade education, and having family environments characterized by discord, divorce, or parental alcoholism or mental illness (268). Many of these high-risk children subsequently experienced problems such as behavioral or learning problems, delinquency, mental health problems, or teenage pregnancy. By the time they were assessed at age 18, however, one-third had grown into competent young adults. By the time the cohort was assessed at age 30, additional numbers of children who had experienced problems during their teens were better off than they had been at age 18. The study identified a number of factors that seemed to protect these children from the potentially negative effects of their environments. Protective factors included the following:

- constitutional characteristics of the children themselves (e.g., a temperament that elicits positive responses from others),
- environmental factors (e.g., having fewer siblings),
- having the opportunity to establish a close relationship with at least one caring adult (not necessarily a parent), and
- the availability of social support outside of the immediate family.

Another longitudinal study followed 456 economically disadvantaged boys (all white) from early adolescence until age 47 (59). From this sample, 75 individuals were identified as high-risk because they had experienced at least 10 negative family characteristics—ranging from a lack of parental supervision, to having an alcoholic father, or having high numbers of social agency contacts. Preliminary data indicate that boys who were rated as most competent as adults tended also to have been rated as competent as boys and were less likely to have exhibited emotional problems as boys.

Another study involved interviews of 68 rural black adolescents who had been identified by their teachers as being academically and socially successful indicated that the adolescents had supportive family relationships, extensive social networks outside of the family, active participation in school and church activities, a strong future orientation, and identification with positive role models (117). This was a cross-sectional study rather than a longitudinal one and did not follow the adolescents over time. The study also did not provide information on less successful adolescents. Thus, it is not really possible to determine the variables that actually led to the adolescents' success.

Hopeful findings about resilient children and adolescents should not be taken to suggest that "extreme poverty ultimately presents no problems to the next generation or that benign neglect is an appropriate solution to desperate social problems" (126). Instead they should be taken to suggest that need for additional research to improve the knowledge of the factors that make a long-term difference in the lives of children and adolescents growing up in poverty or other adverse circumstances. The findings from such research could be used to design societal interventions that enable such children and adolescents to live healthier and longer lives (126).

provide critical information about needs and the etiology of problems, the pronounced lack of information about the variables associated with positive outcomes limits the identification of pathways to health and the maintenance and support of health-enhancing characteristics.

Research on so-called "resilient" children and adolescents is summarized in box 18-A. This research generally suggests that having access to supportive individuals and networks and having the ability to draw upon this support (social competence, greater intelligence) are factors that help children

Table 18-1—Reported Health Status of U.S. Adolescents Ages 10 to 18, by Family Income, 1988[a]

Family income and age	Number of persons at family income levels	Reported health status (percent distribution)				
		Excellent	Very good	Good	Fair	Poor[b]
Under $10,000						
All ages (10 to 18)	3,676,000	35.3%	25.6%	31.9%	6.3%	—*
10 to 14 years	1,807,000	35.8	24.4	33.7	5.1	—*
15 to 18 years	1,869,000	34.8	26.7	30.2	7.3	—*
$10,000 to $19,999						
All ages (10 to 18)	4,880,000	42.9%	27.8%	24.8%	3.9%	—*
10 to 14 years	2,633,000	44.5	29.0	23.4	2.4	—*
15 to 18 years	2,247,000	41.0	26.4	26.5	5.6	—*
$20,000 to $34,999						
All ages (10 to 18)	7,491,000	53.1%	27.4%	17.0%	2.3%	—*
10 to 14 years	4,213,000	55.1	26.6	16.1	2.2	—*
15 to 18 years	3,278,000	50.5	28.5	18.2	2.4	—*
$35,000 or more						
All ages (10 to 18)	10,576,000	63.0%	23.7%	12.3%	0.9%	—*
10 to 14 years	5,665,000	64.4	22.7	11.8	0.9	—*
15 to 18 years	4,911,000	61.3	24.8	12.9	0.9	—*

[a] The data presented in this table are from the National Health Interview Survey, a continuing nationwide sample survey of the civilian noninstitutionalized population in which personal household interviews are used to collect data on demographic characteristics, illness, injuries, utilization of health resources, and other health topics. This survey uses proxy interviews (generally with a parent) for all persons under age 18.

[b] Entries marked with an asterisk did not meet the requisite standard for reliability.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1988 National Health Interview Survey, Hyattsville, MD, 1989.

overcome adverse circumstances. Further research to identify the components of resiliency among adolescents from disadvantaged backgrounds could be helpful in developing effective interventions.

Health Status of Adolescents by Family Income Level

As noted above, the National Health Interview Survey is one of the few sources of national data on U.S. adolescents' health status by family income level. The National Health Interview Survey is a survey of a sample of the civilian noninstitutionalized population and thus does not include adolescents who are homeless or in institutions (e.g., correctional institutions for juvenile offenders, homes for dependent and neglected children, homes and schools for the mentally or physically handicapped, or homes for unwed mothers). As discussed elsewhere in this report, homeless adolescents are at high risk of experiencing a variety of physical and mental health problems and typically lack access to a regular source of health care.[17] Adolescents in juvenile justice facilities are also at particular risk.[18]

In the 1983 and 1985 National Health Interview Surveys, U.S. adolescents ages 10 to 18 from poor families were significantly less likely to be reported to be in excellent health than were adolescents from nonpoor families (37.5 percent of poor v. 55.9 percent of nonpoor) (157). Adolescents from poor families were also considerably more likely to be reported to be in fair or poor health than were adolescents from nonpoor families (7.3 percent of poor v. 2.3 percent of nonpoor) (157).

The 1988 National Health Interview Survey had similar findings. As shown in table 18-1, adolescents in families with incomes under $10,000 were far less likely than adolescents in higher income families to be reported to be in excellent health. Adolescents in families with incomes under $10,000 were also far more likely than other adolescents to be reported to be in fair health (238).

The 1988 National Health Interview Survey further found that adolescents in the lowest income families experienced more restricted-activity days due to acute and chronic conditions than did adolescents in higher income families. As shown in

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[17] See ch. 14, "Homelessness: Prevention and Services," in Vol. II.

[18] See ch. 13, "Delinquency: Prevention and Services," in Vol. II.

Table 18-2—Reported Restricted-Activity Days Among U.S. Adolescents Ages 10 to 18, by Family Income, 1988[a]

Family income and age	Reported restricted-activity days per person		
	All restricted-activity days[b]	Bed-disability days[c]	School- or work-loss days[d]
Under $10,000			
All ages (10 to 18)	11.8	5.8	6.7
10 to 14 years	11.4	5.7	6.9
15 to 18 years	12.3	5.8	6.5
$10,000 to $19,999			
All ages (10 to 18)	9.1	4.2	5.0
10 to 14 years	8.1	3.8	4.5
15 to 18 years	10.4	4.7	5.7
$20,000 to $34,999			
All ages (10 to 18)	8.4	4.0	4.8
10 to 14 years	8.6	3.9	4.5
15 to 18 years	8.2	4.2	5.3
$35,000 or more			
All ages (10 to 18)	8.0	3.9	4.1
10 to 14 years	7.5	3.8	4.2
15 to 18 years	8.6	4.0	4.1

[a] The data presented in this table are from the National Health Interview Survey, a continuing nationwide sample survey of the civilian noninstitutionalized population in which personal household interviews are used to collect data on demographic characteristics, illnesses, injuries, utilization of health resources, and other health topics. This survey uses proxy interviews (generally with a parent) for all persons under age 18.

[b] *Restricted-activity days* are unduplicated counts of bed-disability, work-loss, and school-loss days, as well as other days during which a person cuts down on his or her usual activities.

[c] A *bed-disability day* is a day on which a person stays in bed for more than half of the daylight hours (or normal waking hours) because of a specified illness or injury.

[d] A *school-loss day* is a day on which a child did not attend school for at least half the normal school day because of a specific illness or injury. A *work-loss* day is a day on which a person did not work at his or her job for at least half of the normal workday because of a specific illness or injury.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1988 National Health Interview Survey, Hyattsville, MD, 1989.

table 18-2, adolescents in families with incomes under $10,000 were reported to experience an average of 11.8 restricted-activity days per person in 1988 (238). This average included 6.7 school-loss days per person. Adolescents in families with incomes of $10,000 or more were reported to experience fewer restricted-activity and school-loss days than adolescents in the poorest families.

Overall, the 1988 National Health Interview Survey found that 9.8 percent of adolescents in families with incomes under $10,000 and 5.1 percent of adolescents in families with incomes of $35,000 or more were reported to experience activity limitations as a result of chronic conditions (238). The 1983 and 1984 National Health Interview Surveys found that adolescents in poor families were significantly more likely to suffer from chronic disabling conditions—e.g., mental disorders, diseases of the respiratory system, and diseases of the musculoskeletal system and connective tissue—than were nonpoor adolescents (8.8 percent of poor v. 6.0 percent of nonpoor) (157).[19]

Some researchers have found that adolescents living in poverty are at increased risk of attending schools which are characterized by "poorly prepared teachers, inadequate educational facilities, ineffective administrators, and low teacher expectations" (71).[20] Some poor adolescents may have to drop out of school because of family economic problems (71). Others may drop out because of academic difficulties, disciplinary problems, or pregnancy (272). Adolescents who drop out of school or otherwise become educationally disadvantaged are likely to be unprepared to fill available jobs (119).

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[19] Chronic physical health problems among adolescents are discussed in ch. 6, "Chronic Physical Illnesses: Prevention and Services," in Vol. II.

[20] For a discussion of how school environments affect adolescents, see ch. 4, "Schools and Discretionary Time," in Vol. II.

Poor urban neighborhoods are frequently typified by high rates of crime, decaying and crumbling buildings, open drug sales, and lack of employment and educational opportunities (124,130,142). Living in a poor inner-city area increases the likelihood that an individual will be a victim of crime. For crimes of violence, the victimization rate for adolescents in inner cities is higher than that for residents of urban and suburban areas (71).

Living in poverty, especially in urban areas, is associated with an increased likelihood of early sexual activity and teenage pregnancy (68,141).[21] The causal relationships between poverty and increased levels of teenage pregnancy are not well understood. There is some evidence that adolescents from socioeconomically disadvantaged families tend to initiate sexual activity at an earlier age than adolescents from nondisadvantaged families (149a). There is also some evidence that adolescents from poor families may be less likely than adolescents from other families to use some form of contraception at first intercourse (84) or to continue using contraception (52). Poor adolescents who become pregnant are less likely to have an abortion and less likely to give their child up for adoption than adolescents from less disadvantaged backgrounds (149a).

There is little information available about the relationships between social class and income differences and the use of alcohol, illegal drugs, or tobacco.[22] There is some evidence from one longitudinal study, however, that amount of available spending money and family income are positively related to substance use, presumably because adolescents with more economic resources are more able to purchase alcohol or drugs. However, another study found that working class adolescents were more likely to use hard drugs, but this difference by family income was found for only 1 year of the longitudinal survey (51). Yet another study found that lower income adolescents are more likely to smoke cigarettes than adolescents from families with higher incomes (55).

A number of researchers have found no relation between social class and self-reported delinquency (e.g., 81,269), but others have found that poorer adolescents are more likely than those of higher incomes to commit serious crimes.[23]

Access to Health Services by Poor Adolescents

Patterns of Health Care Utilization by Poor Adolescents

Although data on the patterns of health care utilization among poor adolescents in this country are scarce, these patterns appear to differ from the patterns among nonpoor adolescents (157). The 1983 and 1984 National Health Interview Surveys found that even though adolescents in the lowest income families are reported to be in poorer health than other adolescents, they are somewhat more likely than nonpoor adolescents to wait 2 or more years between physician contacts (157). On average, poor adolescents waited 2 years between physician visits and nonpoor adolescents waited 1.8 years (157). Furthermore, poor adolescents whose activities are limited by chronic health problems are reported to have significantly fewer physician visits (5.3 visits per person per year) than nonpoor adolescents whose activities are similarly limited (7.3 physician visits per person per year) (157).

Interestingly, the 1988 National Health Interview Survey found that adolescents ages 10 to 18 in families with incomes under $10,000 had more hospital stays reported than adolescents in families with higher incomes. As shown in table 18-3, even when hospital stays for deliveries are excluded, poor adolescents in families with incomes under $10,000 had more hospital stays than other adolescents. This finding suggests that when poor adolescents do finally seek care, their health problems may be more severe, but alternative explanations are possible (238).

Barriers to Access for Poor Adolescents

Lack of money is a major barrier to access to health services for poor adolescents. For some adolescents, including poor ones, the effect of lack of money on having access to services is attenuated by health insurance. As discussed elsewhere in this report, however, significant numbers of U.S. adoles-

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[21] For a general discussion of pregnancy among adolescents, see ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

[22] For a general discussion of the use of alcohol, illegal drugs, and tobacco among adolescents, see ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II.

[23] Data on delinquency and studies examining the relationships between family income and delinquency are discussed in ch. 13, "Delinquency: Prevention and Services," in Vol. II.

Table 18-3—Reported Number of Hospital Discharges Among U.S. Adolescents Ages 10 to 18, by Family Income, 1988[a]

	Reported number of hospital discharges per 100 persons[b]	
	All causes	Excluding deliveries
Under $10,000		
All ages (10 to 18)	6.9	4.7
10 to 14 years	—*	—*
15 to 18 years	10.6	6.3
$10,000 to $19,999		
All ages (10 to 18)	6.1	4.2
10 to 14 years	—*	—*
15 to 18 years	10.7	6.5
$20,000 to $34,999		
All ages (10 to 18)	4.0	3.6
10 to 14 years	3.6	3.5
15 to 18 years	4.5	3.8
$35,000 or more		
All ages (10 to 18)	3.4	3.2
10 to 14 years	1.7	1.7
15 to 18 years	5.3	5.0

[a] Data are from the National Health Interview Survey, a nationwide sample survey of the civilian noninstitutionalized population in which personal household interviews are used to collect data on demographic characteristics, illnesses, injuries, utilization of health resources, and other health topics. The National Health Interview Survey defines a hospital discharge as any continuous stay of a night or more in a hospital as an inpatient. The discharges shown in this table are discharges from short-stay hospitals (i.e., hospitals or hospital departments in which the type of service provided is general; maternity; eye, ear, nose, and throat; children's; or osteopathic).

[b] Entries marked with an asterisk did not meet the requisite standard for reliability.

SOURCE: U.S. Department of Health and Human Services, Public Health Services, Centers for Disease Control, National Center for Health Statistics, unpublished data from the 1988 National Health Interview Survey, Hyattsville, MD, 1989.

cents are without private or public health insurance, and adolescents in poor or near-poor families are much more likely to lack health insurance than others.[24] In 1988, about one-third of the 5.3 million U.S. adolescents living in poor families—or about 1.7 million adolescents—did not have health insurance coverage (107). That year, an additional 932,000 adolescents in near-poor families were also without coverage (107).

As discussed elsewhere in this report, adolescents who have health insurance coverage, whether private or public, do not always have access to the services they need.[25] Private health insurers often place restrictions on the services most likely to be needed by adolescents (e.g., mental health care, substance abuse treatment, maternity care and related services, preventive services, services provided by nonphysician providers, and dental care). Even if appropriate benefits are available, adolescents who are concerned about confidentiality may be reluctant to seek care from providers if their private health plan requires parents to submit a claim for reimbursement (as most do). The services offered to eligible adolescents by Medicaid vary widely by State.

Distance from service sites and lack of access to transportation—either because good public transportation is unavailable or because available transportation is costly—are also potentially important barriers to seeking care for people who are economically disadvantaged. In addition, certain types of services, such as mental health services, may be less available in poor areas (34). Although data specific to adolescents are generally lacking, it seems reasonable to assume that these concerns are also important barriers to service for poor adolescents.

Services and Interventions To Increase Access to Health Services Among Poor Adolescents

Various approaches have been developed to address the health-related needs of adolescents living in poverty. Apart from Medicaid and other Federal programs for low-income people discussed in the next section of this chapter, there have been some attempts to make health and related services more accessible to adolescents living in poverty by providing affordable, comprehensive services in community-based settings.[26]

As discussed elsewhere in this report, a national demonstration project funded for 4 years beginning in 1982 by the Robert Wood Johnson Foundation enabled 20 teaching hospitals to work in concert with 54 community-based agencies to implement programs of community-based, comprehensive services for young people in inner-city communities believed to be at high risk for serious socioeconomic and medical problems (49,116,187).[27]

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[24] For a discussion of the number of poor and other adolescents without health insurance, see ch. 16, "Financial Access to Health Services," in this volume.

[25] The barriers to utilization of services by adolescents with health insurance coverage are discussed in ch. 16, "Financial Access to Health Services," in this volume.

[26] Additional information on efforts to deliver comprehensive health and related services to adolescents is presented ch. 15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents," in this volume.

In the first 2 years of the comprehensive clinics' operation, about two-thirds (64 percent) of the young people who visited the clinics were ages 15 to 19; the clinics were also used by young people ages 20 to 24 (21 percent of patients) and ages 10 to 14 (15 percent of patients) (49). Researchers found that adolescents attending the Robert Wood Johnson-funded comprehensive clinics that were specially geared toward adolescents were more likely to disclose behavioral and lifestyle problems to their clinical providers than adolescents attending comparison sites; consequently, larger proportions of adolescents attending the comprehensive clinics received care for such problems (49). Despite their better identification and treatment capabilities for adolescents, however, the comprehensive clinics were not able to effect greater improvements in selected health problems (including persistent depressive symptoms, unmet contraceptive needs, and heavy alcohol or drug use) than the comparison sites (49). The researchers were also disappointed in the ability of the comprehensive clinics to reach adolescent male clients, as adolescent males in inner cities are at especially high risk of problem behaviors.

Earls and colleagues suggest three reasons for the failure of the Robert Wood Johnson-funded projects failed to demonstrate differences in health outcomes: 1) the followup period of 1 year may have been too brief; 2) lack of adolescent-specific skills among primary care providers (and lack of time for funded providers to develop specialized skills); and 3) it may be difficult for medical clinics alone to make a difference in difficulties that are deeply embedded in the economic and social contexts from which some adolescents come (49).

Recently, the Robert Wood Johnson Foundation began funding a longer-term project that placed adolescent clinics in school settings in medically underserved areas. This project is still underway, and the health outcomes for adolescents attending the school-linked clinics have not been evaluated.

Several nongovernmental programs have sought to provide poor inner-city adolescents with alternatives to poor urban street life and to enhance their life options.

- The privately funded Kansas City Youthnet program uses extensive outreach to recruit young people in poor urban areas to participate in programs of athletics, dance, theater, and art instead of joining drug gangs (89). In its first year, the Kansas City Youthnet program contacted some 3,000 adolescents ages 13 to 16.
- A program sponsored by the Youth Services Unit of the Bayview-Hunter's Point Foundation provides daily counseling to 12- to 22-year-olds living in poverty in the San Francisco area and experiencing difficulty in school or with the juvenile justice system as a result of involvement with drugs (16). This program provides a range of additional services, including recreation, mutual support groups, and opportunities to perform court-required community service or restitution activities.
- The University of Illinois at Chicago sponsored a workshop on medical careers for inner-city teens designed to encourage students to ignore negative messages, and pursue positive options (181). Students were introduced to black medical students who had grown up in poverty, given tours of the medical school, and provided with advice about how to prepare for college.

Unfortunately, none of these programs for poor inner-city adolescents has been systematically evaluated.

Major Federal Programs Pertaining to Poor Adolescents

In 1989, OTA held a workshop on the Federal role in adolescent health and conducted a survey of numerous Federal agencies thought to be involved in adolescent health. As discussed in the next chapter of this Report, many Federal agencies have programs that are relevant to U.S. adolescents, but it is almost impossible to get a firm sense of the impact of Federal programs on adolescents' lives.[28] Few Federal agencies were able to break out amounts budgeted specifically for adolescents, and OTA found both overlap and fragmentation in the overall Federal approach to adolescent health issues. The

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[27] The evaluation of the Robert Wood Johnson Foundation program for high-risk young people and its support of SLHCs is described in more detail in ch. 15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Health Services to Adolescents," in this volume.

[28] The findings of the OTA survey of Federal agencies thought to be involved in adolescent health is described in ch. 19, "The Role of Federal Agencies in Adolescent Health," in this volume.

Federal agencies surveyed by OTA were not asked to disaggregate program information as it applied to adolescents of differing socioeconomic levels. Their general inability to provide adolescent-specific information, however, makes it doubtful that they would have been able to provide adolescent-specific information by income level.

Various programs of DHHS and other Federal agencies that are intended to help low-income persons are described below to provide a rough sense of the Federal approach to the issues affecting poor and near-poor adolescents.[29] Unfortunately, the description or programs below provides little sense of the actual impact of Federal programs on the lives of individual adolescents living in poor and near-poor families. One way to get a sense of that would be to conduct an interview survey of poor adolescents in which their use of federally funded programs could be assessed in relation to their needs.

ACTION

ACTION administers several Federal domestic volunteer service programs that provide human services to disadvantaged, poor, and elderly Americans. ACTION's Office of Domestic Operations sponsors a number of efforts that affect adolescents. In fiscal year 1988, there were 469,000 ACTION volunteers, and ACTION had a budget of about $163 million (1). With this budget, ACTION supported the Retired Senior Volunteer Program ($30.6 million), the Foster Grandparent Program ($57.4 million), the Senior Companion Program ($23.1 million), Volunteers in Service to America, the Student Community Service Program, Citizen Participation Program and the Program Demonstration and Development Division (1). Although ACTION's budget is not broken down in a format that separated expenditures, the agency estimates that its fiscal year 1990 budget request for adolescents was about $16 million (5).

The Retired Senior Volunteer Program provides opportunities for retired persons age 60 and over to serve as volunteers in schools, museums, libraries, hospices, and a range of other public and private nonprofit organizations (1). In 1988, there were about 750 projects involving about 400,000 volunteers. Information on the number of adolescents served by these projects is not available. However, some of the projects emphasize substance abuse prevention and intergenerational assistance.

The Foster Grandparent Program provides direct benefits (e.g., stipend, transportation, meal assistance, annual physical examination) to low-income individuals ages 60 and over who work 20 hours a week with children and adolescents who have special needs (1). In fiscal year 1988, the Foster Grandparent Program sponsored 252 projects (1). That year, the program served about 70,000 young people, including about 25,500 ages 6 through 12 and 15,400 ages 13 through 20 (2). Typically, the youth served by the program are at risk of drug or alcohol use, are in the delinquent detention system, are pregnant or parenting, or are mentally, physically, or emotionally disabled (1).

The VISTA program tries to help low-income people become self-sufficient by supporting projects sponsored by local public and private nonprofit organizations (1). In fiscal year 1988, there were 612 VISTA projects and 5,048 VISTA volunteers (1). That year, 244 VISTA projects focused on youth. As of August 31, 1989, 15 VISTA projects involving 66 volunteers were focusing on juvenile health, including the prevention of adolescent pregnancy, substance abuse, suicide, and violence (5).

The Student Community Service Program, a program begun in 1987, funds projects that enable high school and college student to work as volunteers to help eliminate poverty-related problems. As of October 1, 1989, ACTION was funding 121 Student Community Service Projects (3,4). For fiscal year 1990, the estimated budget for the Student Community Service Program was $893,000 (24). In 1988, an estimated 28,000 students provided more than 850,000 hours of community service in various settings, such as Head Start programs, juvenile diversion programs, shelters, and soup kitchens (1).

ACTION's Program Demonstration and Development Division was created, in part, to award demonstration grants to organizations that have the potential to generate volunteer activity within a community and have the ability to serve as a model for other organizations. In fiscal year 1988, the Division awarded $2.6 million in demonstration and other grants for 79 projects (1). Thirteen grants supported projects using volunteers to establish illicit drug use prevention networks either statewide or in low-income communities. Three grants supported efforts to alleviate problems faced by at-risk youth (e.g., youth in foster care). One supported a network to place low-income youth with volunteer mentors.

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[29] Many, if not most, Federal health-related programs for adolescents are probably directed to or have an emphasis on low-income adolescents. This approach is consistent with the Federal emphasis on providing a "safety net" for those who are the most disadvantaged in this country (e.g., 180).

The role of ACTION, and other Federal and local agencies, in promoting youth service opportunities for adolescents should be expanded by passage of the National and Community Service Act of 1990 (Public Law 101-610). The legislation emphasized opportunities for disadvantaged children, adolescents, and young adults.

U.S. Department of Health and Human Services

Each of the following four major components of DHHS has programs relevant to low-income populations:

- the Family Support Administration (FSA),
- the Health Care Financing Administration (HCFA),
- the Office of Human Development Services (OHDS), and
- the Public Health Service (PHS).[30]

Family Support Administration (FSA)—FSA in DHHS administers various programs intended to strengthen the American family, especially low-income families (213). According to FSA, the major thrust of its efforts is to prevent chronic welfare dependency through the provision of support services (212).

FSA's *Office of Family Assistance* administers the Aid to Families With Dependent Children (AFDC) program and the Job Opportunities and Basic Skills Training (JOBS) program. AFDC, which is funded jointly by the Federal and State governments, is the largest cash assistance program serving needy families with children (215). Under Title IV-A of the Social Security Act, AFDC funds are made available to States to maintain and strengthen family life by providing financial assistance and care to needy dependent children in their homes or the homes of caretakers relatives. AFDC has a twofold statutory mission: 1) to assist families with dependent children meet an immediate financial need; and 2) to help parents in these families become self-sufficient (213). AFDC programs are administered by the States, and States have wide latitude in deciding how their AFDC programs are to be organized and administered, who is eligible for aid, and how much aid eligible persons receive (215). In fiscal year 1987, 33 percent (2.5 million children) of the child recipients were ages 10 through 18 (215). Another 121,000 adolescents (85 percent of whom where females) received AFDC benefits as heads of household (215).

Under the Family Support Act of 1988 (Public Law 100-485), States can begin to replace their AFDC programs with a comprehensive education, job training, and work experience program known as the JOBS program (213). The JOBS program is designed to provide AFDC families the opportunity to take part in education, job training, and work experience programs that will help them avoid long-term dependence on public assistance programs. Young mothers with children over age 3 with child care services and out-of-school youth ages 16 and over in AFDC homes are expected to participate (212). All States were required to have a JOBS program by October 1, 1990 (213). As discussed elsewhere in this Report, the JOBS program, if well-implemented, could have a substantial impact on adolescent parents.[31]

FSA's *Office of Child Support Enforcement* supports State efforts to enforce support obligations owed by absent parents to their children (213). Under the Child Support Enforcement Program, established in 1975 as part D of title IV of the Social Security Act, States and territories provide direct services to individuals and families to enable them to collect child support from absent parents (214). FSA's Office of Child Support Enforcement helps States to develop, manage, and operate their programs, and the Federal Government shoulders the preponderant share of administrative costs of the program ($745 million (70 percent of the total) in fiscal year 1987 [214]). An estimated 8.8 million mothers rearing children alone could potentially benefit from these services, but the number of adolescents potentially affected is unknown. In fiscal year 1987, $3.9 billion in child support was collected and $278.5 million was returned to AFDC families, the net amount returned to families with *adolescent* children is not available. Another $2.5 billion was collected on behalf of non-AFDC families (214), but the net amount returned to families with adolescents is not available.

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[30] In recognition of existing Federal fragmentation in attempts to assist poor families, the DHHS recently announced a reorganization of several DHHS programs for children and families (225). The reorganization was not complete as this Report went to press. The programs intended to be affected included the Family Support Administration, the Office of Human Development Services, and the maternal and child health block grants program in the Bureau of Maternal and Child Health (HRSA) (225). Medicaid and programs outside DHHS would not be affected by the reorganization.

[31] See ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

FSA's *Office of Community Services* administers several programs intended to assist poor people, including the community services block grant. Though the community services block grant, FSA provides annual Federal funding to States, territories, Indian tribes, and tribal organizations to help them provide a wide range of services and activities to local communities to assist low-income persons (213). Community service block grant funds are primarily used to meet employment, education, housing, income management, energy, health, and emergency needs of the poor (213). What portion of block funds goes to meet the needs of poor and near-poor adolescents is not known.

FSA's Office of Community Services also administers discretionary community service grants, low-income home energy assistance grants, and emergency community services for the homeless grants. Discretionary community service grants are made directly to public and private nonprofit organizations for a wide range of activities, including economic development, rural housing, rural community facilities, assistance to migrants and seasonal farm workers, community food and nutrition, projects that involve innovative approaches to deal with particularly critical needs or problems of the poor, and recreational activities for low-income youth (213). The low-income energy assistance program provides Federal grants to States, territories, Indian tribes and tribal organizations that wish to assist low-income households in meeting the costs of home energy. The emergency community services homeless grant provides annual funds to States, territories, and federally recognized Indian tribes to provide comprehensive services (emergency food and shelter, employment and educational training, medical care, counseling, case management, and related services) to homeless individuals and families.[32] In part because these programs almost all involve grants to States and/or other entities (e.g., Indian tribes), the amounts expended specifically for adolescents are generally not available from the Federal Government.[33]

Health Care Financing Administration (HCFA)—HCFA in DHHS administers Medicaid, a Federal/State program established in 1965 under Title XIX of the Social Security Act to increase access to health services for poor people (218).

In 1988, there were about 23 million Medicaid recipients, including about 10 million dependent children under age 21, and total benefit payments were $51.6 billion ($29 billion Federal and $22.6 billion State moneys) (219). An estimated 4.58 million U.S. adolescents ages 10 to 18 had Medicaid coverage at some point in time during fiscal year 1988; and Federal and State Medicaid expenditures for these adolescents totaled approximately $3.322 billion (220). In 1988, HCFA estimated that adolescents made up 17.1 percent of Medicaid enrollment and accounted for 6.9 percent of national Medicaid expenditures (220).[34]

Title XIX of the Social Security Act requires that, in order to receive Federal matching funds, States offer a specified minimum benefit package in their Medicaid program. In addition to offering hospital inpatient and outpatient services, physician services, skilled nursing home care for adults, laboratory and X-ray services, nurse midwife services, family planning services, rural health clinic services, and transportation services, State Medicaid programs must provide early and periodic screening, diagnosis, and treatment services for eligible individuals under age 21 (218). Under Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, eligible children must be screened and treated for vision, hearing, and dental problems; their growth and development must be checked; and they must be immunized against infectious diseases (218,219). The funding of abortions under Medicaid is prohibited.

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[32] Federal programs for homeless adolescents are addressed in ch. 14, "Homelessness: Prevention and Services," in Vol. II.

[33] In addition to being involved in these legislatively mandated programmatic efforts, FSA oversaw a panel on teen pregnancy prevention. Materials developed during the initiative, which took place during the Reagan administration, were transferred to the Office of Adolescent Pregnancy in the Public Health Service.

[34] For further discussion, see ch. 16, "Financial Access to Health Services," and app. C, "HCFA's Method for Estimating National Medicaid Enrollment and Expenditures for Adolescents Ages 10 Through 18," in this volume.

Although the Medicaid program is funded by the State and Federal Governments, it is administered by the States. States have broad discretion in determining, within Federal guidelines, which groups their Medicaid programs will cover and the financial criteria for Medicaid eligibility. States are required, however, to provide Medicaid coverage for most recipients of Federal and/or State income maintenance assistance programs, including recipients of AFDC, recipients of adoption assistance and foster care under Title IV-E of the Social Security Act. States are also required to cover children ages 1 through 6 and pregnant women who meet the State's AFDC financial requirements, and to cover pregnant women (and infants to age 2) if their income is at or below the Federal poverty level.

Enrollment in Medicaid appears to have a strong effect on the utilization of health care by poor adolescents, increasing their level of utilization to levels similar to those of nonpoor adolescents (157). As discussed elsewhere in this report, however, many adolescents living in poverty are not covered by Medicaid.[35] In 1988, fewer than half of U.S. adolescents living in families with incomes below the Federal poverty level were covered by Medicaid (107). Even among adolescents in the poorest families, those with incomes under half the poverty level, only half are covered by Medicaid.

Furthermore, even for adolescents who are eligible, Medicaid does not ensure access to health services. One problem is that coverage of some services (e.g., dental services, mental health services) is limited (203). Another problem for poor adolescents who are eligible for Medicaid is low levels of physicians' participation in the Medicaid program (200,276). Physician participation in Medicaid is particularly low among two specialties of importance to adolescents, gynecologists and psychiatrists (200). Other potential barriers to the utilization of services include adolescents' concerns about confidentiality.[36]

Office of Human Development Services (OHDS)—OHDS within DHHS oversees various social and economic development programs for poor children and youth, families, Native Americans, persons living in rural areas, disabled people and elderly people (226). Like FSA, this agency sees as its major mission the promotion of self-sufficiency among the people it serves (223). In fiscal year 1988, appropriations for OHDS programs were $5.2 billion (226). The largest appropriation was for social services block grants ($2.7 billion), followed by appropriations for the Administration for Children, Youth, and Families ($1.5 billion), family social services ($811 million), the Administration on Developmental Disabilities ($92.9 million), and the Administration for Native Americans ($29.7 million). Comprehensive counts of OHDS services specifically for adolescents—thus, including low-income adolescents—cannot be readily provided. It is likely, however, that many OHDS services provided to adolescents are provided to low-income adolescents.

The social services block grant program, authorized under Title XX of the Social Security Act as amended by the Omnibus Budget Reconciliation Act of 1981 (OBRA-81, Public Law 97-35), provides Federal assistance to States for social services directed at five goals: 1) achieving or maintaining economic self-support; 2) achieving or maintaining self-sufficiency; 3) preventing or remedying neglect, abuse, or exploitation of children or adults; 5) preventing or reducing inappropriate institutional care by providing for community-based care, home-based care or other forms of low-intensity, lower cost care; and 5) securing referral for institutional care, where appropriate (222). States and other jurisdictions that are eligible to receive social services block grant funds are given wide discretion in determining what services will be provided, who will be eligible for services, and how the funds will be distributed within the State (222). OBRA-81 eliminated Federal mandates regarding priority recipients and eliminated provisions relating to the targeting of services not all services to low-income individuals or families. There is little information on the use of Title XX funds by States. According to OHDS, however, 22 States used fiscal year 1988 social services block grant funds to provide indigent children and adults with supportive health services to identify health needs and services available to help people remain in their own homes; secure admission to medical institutions; assess the appropriateness of institutional placements; and ensure the continuity of treatment (223). The number of adolescents affected is unknown.

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[35] See ch. 16, "Financial Access to Health Services," in this volume.

[36] See ch. 17, "Consent and Confidentiality in Adolescent Health Care Decisionmaking," in this volume.

OHDS' *Administration for Children, Youth, and Families* administers a number of programs relevant to children and adolescents (226). The Administration's Head Start Bureau funds the Head Start program for low-income preschool children. The Administration's Family and Youth Services Bureau administers the Runaway and Homeless Youth Act, which seeks to address the crisis needs of runaway and homeless youth and their families.[37] In fiscal year 1988, about 340,000 young people were served by the 327 federally funded runaway centers across the country (226). Funding for the centers was about $22 million (226).

The Administration's Children's Bureau administers provisions of the Child Abuse Prevention and Treatment Act and has within it the National Center on Child Abuse and Neglect (226). The Children's Bureau provides Federal support for child welfare services (including funds for Title IV-E foster care maintenance and adoption subsidies for children who are hard to place) and provides Independent Living Formula Grants to States that assist adolescents in foster care make transitions into the world of work (223). How many poor adolescents are affected is unknown.

OHDS' *Administration on Developmental Disabilities* administers the Developmental Disabilities Act and supports programs for developmentally disabled persons of all ages. How many poor adolescents are affected is unknown.

OHDS has several special initiatives for adolescents using discretionary funds. It may be that many of these programs focus on adolescents who are already low-income or who, by reason of their own behaviors or life circumstances, are at risk of eventually becoming dependent on public assistance. In 1986, OHDS and other agencies in DHHS funded the Youth Self-Sufficiency initiative (Youth 2000) in concert with the U.S. Department of Labor and others (e.g., the Business Roundtable). A public-private partnership was formed to discuss the needs of at-risk youth and to ensure their economic and social self-efficiency, and several grants were made to attempt to meet the multiple needs of youth in a comprehensive manner.

Public Health Service (PHS)—PHS supports a wide variety of efforts to improve the physical and mental health of Americans. At least two PHS agencies administer programs that are specifically intended to help poor people:

- the Health Resources and Services Administration (HRSA), and
- the Office of the Assistant Secretary of Health (OASH).

The Health Resources and Services Administration (HRSA)—HRSA oversees a number of programs of general health services and resources issues relating to access, equity, quality, and cost of care.

HRSA's *Bureau of Health Care Delivery and Assistance* supports States and communities in their efforts to plan, organize, and deliver health services to medically underserved populations and to special populations at risk (e.g., underserved pregnant women and children, homeless people). The Bureau's Division of Primary Care supports the provision of primary health care services to low-income persons by providing Federal funds for community and migrant health centers (about $426 million in fiscal year 1988) (422). The Bureau's Division of Special Populations Program Development provides Federal grants to organizations to provide health care for the homeless programs ($60 million in fiscal year 1988), comprehensive perinatal care programs for low-income pregnant women and children ($20 million in fiscal year 1988), and other services (242). Specific funding for adolescent health initiatives is not available. On the basis of the average number of adolescent visits to community health centers (CHCs) and migrant health centers, however, the Bureau of Health Care Delivery and Assistance estimates that it spent about $33 million on medical care for adolescents in 1988 (242).

CHCs provide primary health care services (including primary medical care and ancillary services such as laboratory test and X-ray services, plus preventive dental services and family planning services) to medically underserved, disadvantaged populations (241).[38] CHCs are located in areas of the country where there are financial and/or geographic barriers to primary care for a substantial part of the population; they are staffed by personnel on assignment from the National Health Service Corps. About 6 million individuals receive services at CHCs annually (241). Migrant health centers provide comprehensive primary health care to migrant and seasonal farmworkers. The centers are located in over 300 rural areas in 35 States and Puerto Rico and serve about 450,000 migrant and seasonal farmworkers (about 15 percent of the migrant and seasonal farmworker population) annually (242). In 1989, according to the Bureau of Health Care Delivery and Assistance, 814,000 adolescents received medical care in community and migrant health centers; of these adolescents, 117,000 females ages 10 to 14 received family planning services (242). At least 121,000 adolescents received dental care in these centers in 1989 (242).

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[37] See ch. 14, "Homelessness: Prevention and Services," in Vol. II for discussion of runaway and homeless youth centers funded under this act.

[38] OBRA-81 (Public Law 96-35) established a primary care block grant program, and States were given the option to receive block grant funds for CHCs or to administer CHCs under section 330 of the Public Health Service Act.

HRSA's *Bureau of Maternal and Child Health* (formerly the Office of Maternal and Child Health (227a)) administers the maternal and child health block grant programs authorized by Title V of the Social Security Act. It awards maternal and child health block grants to States "to assure access to quality maternal and child health services, especially for those with low incomes and living in areas with limited availability of health services." In fiscal year 1988, the appropriation for the maternal and child health services block grant program was $526 million (240a). Eighty-five percent of this appropriation ($444.3 million) was allocated to State health agencies to assist them in promoting, improving, and delivering maternal and child health services for children with special health needs, and 15 percent ($82.3 million) was set aside for the Bureau of Maternal and Child Health to award on a competitive basis to support special projects of regional and national significance (SPRANS) which contribute to the health of mothers, infants, and children and children with special needs (240a). The amount specific to poor adolescents is not known.

Office of the Assistant Secretary of Health (OASH)—OASH's *Office of Population Affairs* carries out Public Health Service Act Title X and Title XX programs related to adolescent pregnancy, family planning, and population research. The Office of Population Affairs provides Title X funds to public or private nonprofit organizations operating family planning projects for low-income individuals and encouraging family participation when possible.[39] Approximately one-third of all Title X money is specific to adolescents. As of 1989, organizations receiving Title X funds were prohibited from using the money to provide counseling and referral for abortion services except in medical emergencies (54 FR 35440-35441). In a 5-4 decision on May 23, 1991, the U.S. Supreme Court upheld this regulation, despite the concern of some dissenting judges that the regulation "raises serious First Amendment [free speech] concerns."[40]

The Office of Population Affairs also distributes Public Health Service Act Title XX funds for adolescent family life demonstration projects. An average of 60 demonstration grants and seven research grants are funded under Title XX each year. Projects funded under Title XX attempt to establish innovative, comprehensive, and integrated health care services for pregnant and parenting adolescents under age 17. Abstinence from premarital sexual intercourse and adoption as an alternative to abortion are encouraged. Title XX money cannot be used to provide abortion, abortion counseling, or abortion referrals, and adolescents must obtain parental consent before participating in any Title XX program. Title XX programs are not limited to low-income individuals, but Congress has suggested that service areas with a high proportion of low-income families should receive priority when grant applications are considered (Public Health Service Act, Title XX, Sec. 2005).

U.S. Department of Agriculture

The U.S. Department of Agriculture administers a wide range of programs related to farms, nutrition, food, hunger, rural development and the environment. Several programs to make food assistance available to low-income people are administered by the Department's Food and Nutrition Service within the Office of the Assistant Secretary, Food and Consumer Services. Such programs include the Food Stamp Program, the National School Lunch and Breakfast Programs, and the Special Supplemental Food Program for Women, Infants, and Children.

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[39] For further discussion of services provided to pregnant and parenting adolescents under Titles X and XX of the Public Health Service Act, see ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

[40] Justice O'Connor, as cited in *The New York Times*, "Excerpts From Court Ruling Curbing Family Planning Clinics," May 24, 1991, p. A19. In essence, the Federal regulation upheld by the Court bars employees of federally financed family planning clinics from all discussion of abortion with their patients; requires them to inform any woman who inquires about abortion that "the project does not consider abortion an appropriate method of family planning"; and requires a referral to prenatal care (L. Greenhouse, "Five Justices Uphold U.S. Rule Curbing Abortion Advice," *The New York Times*, p. A19, May 24, 1991).

The Food Stamp Program provides low-income individuals and families with children with noncash transfers that can be used only for food. For those participating, the program has been associated with significant improvements in dietary intake (197). According to the U.S. Department of Agriculture's 1977-78 Nationwide Food Consumption Survey, however, only 12 percent of low-income households spending at the full food stamp allotment obtained 100 percent of their recommended dietary allowances, and only a third obtained at least 80 percent (197). Adolescents ages 15 to 17 make up 34 percent of the participants in the Food Stamp Program (206). But all eligible adolescents may not benefit; in 1979, less than 60 percent of all poor households participated in the Food Stamp Program (195). Some observers have suggested improving nutrition for low-income youth by increasing food stamp benefit levels or making sure that people who are eligible receive them (71).

The School Breakfast and School Lunch Programs provide meals for low-income school children free or at a reduced price depending on family incomes. An estimated 24 percent of participants in the School Breakfast Program and 43 percent of participants in the School Lunch Program are in grades 7 through 12 (206). Evaluations of these meal programs have shown that they have a positive effect on the overall caloric intake of participants (195), although they may have other shortcomings.[41] Some observers have suggested extending the programs to all schools in low-income areas (71).

The Special Supplemental Food Program for Women, Infants, and Children is intended to improve the health of low-income pregnant, breastfeeding, and postpartum women, infants and children up to their fifth birthday (206). Federal funds are used to purchase food packages to supplement participants' diets and to provide nutrition education. Females under age 18 make up an estimated 2.8 percent of participants in this program.

Finally, it should be noted that the Department of Agriculture's Extension Service has been developing an agenda to better serve "youth at risk" due to poverty, lack of family support, or negative peer pressure (205).

U.S. Department of Labor

The U.S. Department of Labor has responsibility for fostering U.S. workers' welfare, improving working conditions, and promoting opportunities for employment. The Department's *Employment and Training Administration* has responsibilities related to job training and supports employment and training programs for economically disadvantaged youth Titles II-A and II-B and Title IV.

Titles II-A and II-B of the 1982 Job Training Partnership Act authorize block grants to States. Under Title II-A, training services are offered throughout the year to economically disadvantaged adults and youth. In program year 1989, 40 percent ($715.1 million) of the Title II-A budget was earmarked for adolescents. Title II-B establishes a summer employment program for low-income youth. Funding for Title II-B was $709.4 million for summer 1990 (258).

Title IV of the Job Training Partnership Act authorizes the Job Corps and various other federally administered programs. The Job Corps provides employment and training in primarily residential centers for disadvantaged adolescents and young adults ages 16 to 21 (259). Health care is also provided by Job Corps. In 1989, the U.S. Department of Labor provided $741.8 million for the centers, and there were 100,000 participants in the Job Corps. After completing the program, 66.9 percent of the participants were placed in jobs and 16.7 percent went on for further education.

Racial and Ethnic Minority Adolescents: Issues in the Delivery of Health and Related Services

The U.S. population is increasingly coming to be made up of blacks, Hispanics, Asians, and other racial and ethnic minorities. By the year 2000, an estimated 29 to 31 percent of the new entrants into the U.S. workforce will be from racial and ethnic minority groups, a figure twice that of only a few years ago (66,67). Overall, 26 percent of the workforce—and 26 percent of the overall U.S. population—in 2000 is expected to be from racial and ethnic minority groups and the proportions of blacks, Hispanics, and other minorities (i.e., Asians) are expected to climb steadily throughout the 21st century (67) (see figure 18-5).

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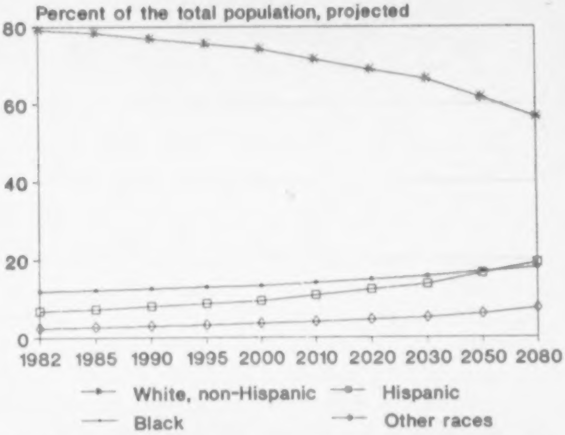
[41] See ch. 7, "Nutrition and Fitness Problems: Prevention and Services," in Vol. II.

What are the implications of these demographic trends for U.S. health policymakers? Currently, about 30 percent of American adolescents ages 10 through 18 are members of racial and ethnic minorities (211). By the year 2010, as many as 38 percent of Americans under the age of 18 will belong to minority groups. This trend is promising in that it will increase the cultural diversity of the United States. But, as noted earlier in this chapter, about half of black, Hispanic, American Indian and Alaska Native, and one-third of Asian adolescents live in poor or near-poor families (see figure 18-3). At least in part because these adolescents live in poverty, and for other reasons which are not entirely clear, black, Hispanic, and American Indian adolescents are at increased risk of experiencing a range of health-related problems, including physical health problems, psychosocial problems, criminal victimization, and teen pregnancy. If the percentage of racial and ethnic minority adolescents increases and the social economic status of racial and ethnic minority groups does not improve, U.S. adolescents' need for publicly financed health care will continue to grow.[42]

Even if the socioeconomic status of racial and ethnic minority groups does improve, there may be a need for "culturally competent" health services for racial and ethnic minority adolescents. The need for culturally sensitive and locally appropriate health services has recently become an increasingly common topic of discussion (e.g., 44,86,185). Questions that have arisen include the following: Are there alternatives to mainstream health care in the United States that are used within particular cultures? Do cultural factors affect some populations' willingness to use certain types of services (e.g., mental health services)? Are there certain cultural norms, strengths, or traditions (e.g., strong, traditional families or church involvement) that "protect" individuals in certain groups from health risks? Are there genetic, cultural, or historic factors that put individuals at risk for health problems? Does the mainstream health care system have certain characteristics that make it less accessible to or less effective for certain population groups? What culture-specific innovations in service delivery have been found to be effective in addressing the health needs of certain groups?

Figure 18-5—Projected Changes in the Racial and Ethnic Makeup of the U.S. Population, All Ages, 1982 to 2080



SOURCE: Office of Technology Assessment, 1991, based on U.S. Department of Commerce, Bureau of Census, *Projections of the Hispanic Population: 1983 to 2080*, Current Population Reports, Population Estimates and Projections, Series P-25, No. 995 (Washington, DC: U.S. Government Printing Office, 1986).

Data on the utilization of health services by racial and ethnic minority adolescents are limited, but existing data suggest that racial and ethnic minority adolescents confront not only economic barriers but also cultural barriers to access. Minority providers and providers trained in cultural awareness are few. Some of the cultural traditions and institutions of different racial and ethnic minority groups—strong family and community ties, for example—may turn out to be resources on which programs that provide health and health-related services can capitalize to provide effective services.

The focus of the discussion that follows is on the delivery of health and related services to five categories of racial and ethnic minority adolescents in which Congress expressed particular interest:

- black adolescents,
- Hispanic adolescents,
- Asian adolescents,

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[42] OTA knows of no adolescent population projections based on socioeconomic status.

- American Indian and Alaska Native adolescents, and
- Native Hawaiian adolescents.[43]

The health and other effects of belonging to a racial or ethnic minority group have not been fully investigated. It is important to note, however, that racial and ethnic minorities and American Indians have been the target of much racism and discrimination in this country (71,185,191). Although civil rights legislation in the 1960s legally removed racial barriers in access to voting and public accommodations, discrimination in many aspects of American life remains (58). Blacks, the largest minority group in the United States, were defined as subordinate and inferior to whites by a racial caste system introduced by slavery (71,72). Asians were legally prohibited from immigrating to the United States by the Chinese Exclusion Act of 1882 and the Oriental Exclusion Act in 1924 that banned all immigration to the United States from Asia. The internment of Japanese families during World War II targeted Japanese Americans for separation from the larger society (148). Throughout the Nation's history, Federal Government policies undermined American Indian cultures (199). Native languages were prohibited from being taught in schools, religious ceremonies and traditional practices were discouraged, and populations were relocated. The impact of the loss of culture faced by many Indians has been cited as a chief contributor to many of the health and social problems confronting the American Indian population today.

Photo credit: Capitol Hill Arts Workshop, Washington, DC

Adolescence is a crucial period for identity formation, and an individual's racial or ethnic minority status takes on a new importance during adolescence.

Recent immigrants to this country may have problems related to their immigration experience. The immigration experience sometimes exposes individuals to special risks that may cause or exacerbate health and mental health problems. Many immigrants from Southeast Asia, for example, left Vietnam, Laos, and Cambodia under extremely adverse and dangerous circumstances; the experience of having been physically and sexually assaulted by sea pirates is not uncommon among adolescent refugees escaping from these war-torn countries (20,62). Many adolescent refugees from Central America left to escape from the horrors of war and economic privation and separated from their families (260). These recent immigrants may have language and other difficulties adjusting to American culture.

Adolescence is a crucial period for identity formation (185). As pointed out by Spencer and

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[43] The attribution of race or ethnicity is sometimes rather arbitrary. For example, many "blacks" have white ancestors, Hispanic people can have white or black ancestry, and American Indians may also have black or white ancestors. Use of these limited categories obscures the diversity found within minority groups (266). Terminology may also change over time. For example, some black Americans are coming to prefer the designation "African-American" over "black." The term "African-American" could, for example, be used to distinguish some individuals who are U.S. citizens from some recent immigrants from Africa and the Caribbean. Because the term "black" is still used by the Federal Government to collect and calculate population, health, and other statistics, and because potential distinctions among "African-Americans" and other "blacks" is as yet not clear, the term "black" has also been used in this Report. Finally, it is important to note that, in terms of Federal health policy, American Indians have a somewhat different relationship with the Federal Government than do other racial or ethnic minorities. In large part, Indian tribes function as "domestic dependent nations," and the U.S. Supreme Court has ruled that special programs for the benefit of Indians are not racial in nature but based on a unique political relationship between Indian tribes and the Federal Government (*Morton* v. *Mancari*, 417 U.S. 535 [1974]; see 199).

Dornbusch in their review entitled "Challenges in Studying Minority Youth," an individual's racial or ethnic minority status takes on a new importance during adolescence (185):

> The adolescent's awareness of minority status is qualitatively different from that of the child. Very young children often think of their race. . .as mutable, something that may change as they grow. . .
>
> In contrast to young children, adolescents have the ability to interpret cultural knowledge, to reflect on the past, and to speculate about the future. With cognitive maturity, minority adolescents are keenly aware of the evaluations of their group made by the majority culture. . .
>
> The minority adolescent's awareness of. . .[the majority culture's] negative appraisals [of the minority group], of conflicting values, and of restricted occupational opportunities can affect life choices and the strategies selected for negotiating a life course.

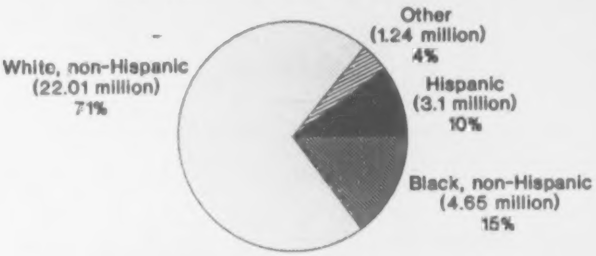
It is particularly important to recognize that racial and ethnic minority adolescents may be faced with "negotiat[ing] a balance between two value systems: that of their own group and that of the majority" (185). Some racial and ethnic minority adolescents may perceive that adhering to the values of the "mainstream culture" is essential to achieving success in that culture but may regard such adherence as forcing them to reject their own ethnic identity (185). Members of minority groups who reject their own culture for that of the "mainstream culture" are sometimes characterized pejoratively by other members of their minority group (e.g., blacks who "act white" may be called "Oreos"; American Indians who "act white" may be called "Apples"; Asians who "act white" may be called "Bananas"; Hispanics who "act white" may be called "Coconuts"). Some minority adolescents may be faced with conflicting role models; others (e.g., some young black males in the inner city), with a lack of role models (185). Some minority females come to devalue their own appearance (185).

According to Spencer and Dornbusch, "Even when they have a positive *personal* identity. . ., minority adolescents may develop ambivalent or negative attitudes towards their own *group*" (185).

Of the strategies for dealing with cultural conflict (alienation, separation, assimilation, and biculturalism), the ability to develop "bicultural competence" appears to offer some advantages (185). Biculturally competent individuals would have the norms of both majority and minority groups available to them; the standard to be used would depend on the situation (185). A requirement to develop a bicultural identity suggests that minority individuals bear an extra load during the critical developmental period of adolescence.

Figure 18-6—Race/Ethnicity of U.S. Adolescents Ages 10 to 18, 1987

Total population ages 10 to 18 • 31 million



SOURCE: Office of Technology Assessment, 1991, based on R. Kronick, Adjunct Professor, University of California, San Diego, CA, calculations based on U.S. Department of Commerce, Bureau of the Census, March 1988 Current Population Survey public use files, 1989.

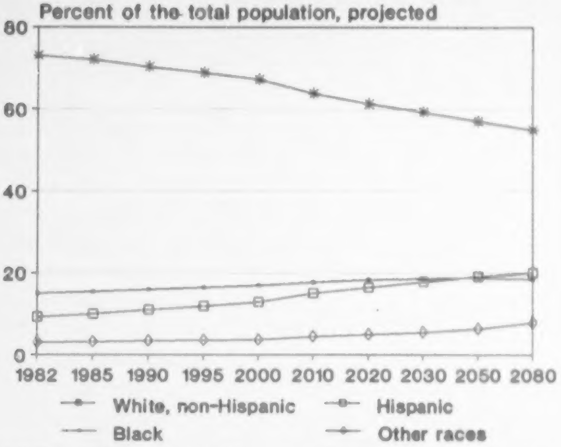
There is some evidence that racial and ethnic minority adolescents today see themselves and their opportunities differently from white adolescents. In a survey of adolescents in grades 7 through 12 in Minnesota, minority adolescents reported worrying more than white adolescents about their future job prospects and their current economic condition; they were also significantly more likely to report being worried about being treated unfairly because of their race (176).

Overview of the Number of Racial and Ethnic Minority Adolescents

As noted above, according to data from the U.S. Department of Commerce, Bureau of the Census, adolescents who are not "white, non-Hispanic" made up about 30 percent of the country's 31 million adolescents in ages 10 through 18 in 1987. As shown in figure 18-6, non-Hispanic black adolescents made up 15 percent of the population of 10- to 18-year-olds; Hispanic adolescents (both black and white) made up about 10 percent of the adolescent population; and other adolescents (including Asians) made up 4 percent of the adolescent population (107).

The percentage of U.S. adolescents who are not "white, non-Hispanic" is growing and in a growing number of cities, localities, schools, and regions of

Figure 18-7—Projected Changes in the Racial and Ethnic Makeup of the U.S. Population Under Age 18, 1982 to 2080



SOURCE: U.S. Department of Commerce, Bureau of the Census, *Projections of the Hispanic Population: 1983 to 2080*, Current Population Reports, Population Estimates and Projections, Series P-25, No. 995 (Washington, DC: U.S. Government Printing Office, January 1986).

the country, those who are *not* "white, non-Hispanic" are numerically dominant. By the year 2010, as many as 38 percent of Americans under the age of 18 will belong to minority groups (see figure 18-7). By the year 2000, Hispanics are expected to be the largest minority group as a result of their high rates of fertility and immigration (73,267,208).

Health Status of Racial and Ethnic Minority Adolescents

Limitations of Data and Research on the Health of Racial and Ethnic Minority Adolescents

Data and research on the health status and health care utilization patterns of racial and ethnic minority adolescents have several limitations. Data on births and deaths in the United States are collected from the States by the National Center for Health Statistics. The National Center for Health Statistics publishes death rates for 72 causes by race (white, black, all other) by 5-year age groups (including 10 to 14 and 15 to 19), but data on deaths for adolescents in many ethnic groups is not readily available. Historically, national health and health services utilization surveys sponsored by the National Center for Health Statistics, such as the National Ambulatory Medical Care Survey and the National Health Interview Survey, have provided little reliable data on the health status or health care utilization patterns of adolescents from racial and ethnic minority groups. Data on certain subgroups of minorities, such as refugee adolescents, the largest portion of whom come from Southeast Asia, are nearly nonexistent (20,118,216). Even when race or ethnicity are considered as variables in research, culture, which is sometimes but not always related to race or ethnicity,[44] is rarely considered as a variable (44,131).

Information about specific health concerns of racial and ethnic minority adolescents is greatly limited by a paucity of reliable, population-based data (21,175). Much of the information available about cultural beliefs and practices of different racial and ethnic minority groups is based on data gathered on adult populations. Little is actually known about the beliefs and practices of adolescents in particular. Especially in the case of recent immigrant families, the beliefs of adolescent members may differ substantially from the beliefs of their parents and grandparents.

Until recently, research on the health-related beliefs and practices of black adolescents has generally been conducted on black adolescents living in urban settings, usually in poverty (e.g., 24a,30,31,63,173). It is questionable whether the findings from such research are applicable to the many black adolescents who do not live in central cities and/or are not poor.[45] According to a recent review by Spencer and Dornbusch, the social science research base on American minority adolescents has broadened somewhat to include some suburban and rural black adolescents, well-functioning minority adolescents from blue-collar families, and economically advantaged racial and ethnic minority adolescents (185). Overall, however, the available research base on racial and ethnic minority adolescents is thin.

A particularly critical limitation of much available current research is that the effects on health status and health care utilization of factors related to race or ethnicity are frequently confounded with effects related to socioeconomic status or other sociodemographic factors (64). When interpreting the results of most small-scale research studies, it is difficult to differentiate between the effects of race and ethnicity and the effects of socioeconomic status (131,175,185).

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[44] According to Cross et al., culture "implies the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group" (44).

[45] While 57 percent of blacks overall live in central cities, 18 percent live in nonmetropolitan areas, and another 25 percent live in metropolitan areas, but outside of central cities (209). And while about half of black adolescents lived in families with incomes below or near the Federal poverty level, nearly one-quarter live in incomes that exceeded 300 percent of the poverty level (107).

In addition, biases and prejudices of the mainstream culture are sometimes reflected when studying racial and ethnic minority adolescents. For example, theories of adolescent development (e.g., Erikson's theories [53,54]) are based on white adolescents, and so may ignore cultural differences between these and black or other minority adolescents and not provide an appropriate framework for understanding the development of minority adolescents (160,191). Additional evidence suggests that there may be a tendency for some minority youth with problems to be referred to different service systems than whites. For example, black adolescents with behavioral problems may be more likely to be referred to the juvenile justice system, while white adolescents with behavioral problems may be more likely to be referred to the mental health system (17,44,46).

Another important limitation of existing research is that most studies with ethnic and racial minorities have been conducted using a problem-focused approach that examines minority groups' disproportionate risk of experiencing various problems, frequently using nonrepresentative samples such as clinical populations or adolescents in institutional settings (21,117,131,185). While the deficit model may be useful for identifying critical areas of need among minorities, it does little to explain the means by which many of these adolescents achieve positive outcomes.

Despite the adversities they confront, many adolescents from poor or otherwise disadvantaged backgrounds have significant cultural and personal strengths that protect them from experiencing some problems or that could potentially attenuate their effects. As noted above, much of the research that does exist on adolescents living in poverty and on racial and ethnic minority adolescents has focused on the "failures" rather than the successes. These failures, however, are not entirely representative. In order to design services that can capitalize on individual and cultural strengths, it would be helpful to have more information about the factors associated with positive outcomes.

Health Problems Experienced by Racial and Ethnic Minority Adolescents

Information on some of the specific types of problems that have been reported for black adolescents, Hispanic adolescents, Asian adolescents, American Indian and Alaska Native adolescents, and Native Hawaii adolescents is presented below. Despite the severe limitations in available information, there is evidence that adolescents from these racial and ethnic minority groups are at increased risk of experiencing some health problems. The reasons are not entirely clear. Whether there are genetic or cultural factors that contribute to the health problems experienced by racial and ethnic minorities has not been fully investigated.

In some cases, racial or ethnic minority adolescents are at reduced risk of experiencing health problems. For reasons that are unclear, for example, black adolescents appear to have lower rates of alcohol and illicit drug use than white adolescents (21,149,228). Black adolescents are also less likely to die from automobile crashes than white adolescents, at least in part because poor black adolescents and those living in inner cities tend to have less access to cars.[46] Suicide rates for black adolescents, although increasing, are also lower than those for white adolescents (75,232).[47] Asian-American adolescents tend to defer involvement in sexual activity and to have lower rates of pregnancy than white adolescents (189).[48]

Black Adolescents—As shown in figures 18-8 and 18-9, black adolescents in this country have considerably higher death rates than white adolescents (238b). Among all U.S. adolescents, adolescent males ages 15 to 19 have the highest death rates. In 1987, the death rate for all adolescent males ages 15 to 19 was 119.6 deaths per 100,000 population; the death rate for black adolescent males in this age group was 144.2 deaths per 100,000 (see figure 18-9). While young white males die primarily from accidents, young black males die primarily from homicide (71). In addition, black males are much

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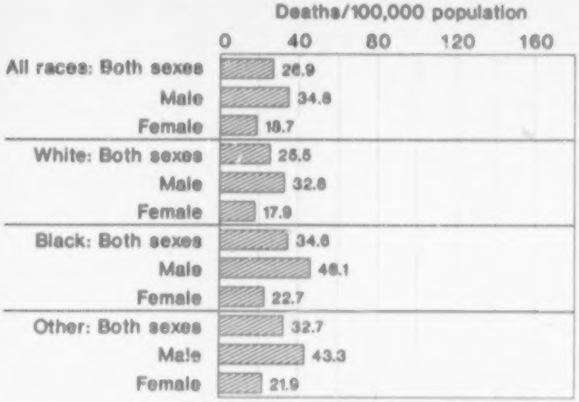
[46] See ch. 5, "Accidental Injuries: Prevention and Services," in Vol. II for further discussion.

[47] See ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II for further discussion.

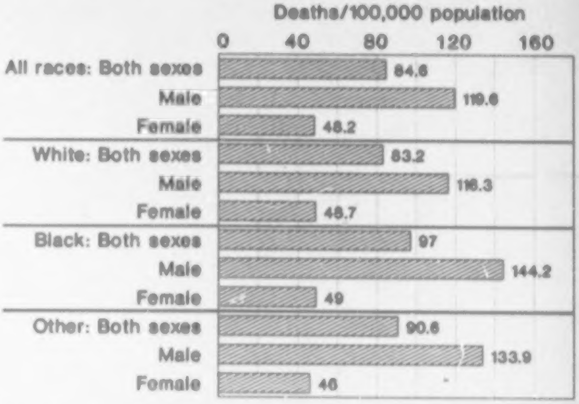
[48] See ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II for further discussion.

Figure 18-8—Death Rates for All Causes for U.S. Adolescents Ages 10 to 14, by Race and Sex, 1987



SOURCE: Office of Technology Assessment, 1991, based on U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1987 mortality data, Hyattsville, MD, 1990.

Figure 18-9—Death Rates for All Causes for U.S. Adolescents Ages 15 to 19, by Race and Sex, 1987



SOURCE: Office of Technology Assessment, 1991, based on U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, unpublished 1987 mortality data, Hyattsville, MD, 1990.

more likely to be victims of police brutality or killed in confrontations with police than whites (166). Black adolescent males are disproportionally at risk for being victims of crime; they are nearly six times more likely to die from homicide than white adolescent males (235). The risk of death from homicide for black males increases if they reside in high-risk neighborhoods, if they use drugs, if they engage in criminal behavior, and if they live in the North Central region. These disparities diminish considerably, however, when socioeconomic status is held constant (46).[49]

The second leading cause of death among young black males is accidents. The proportion of accidental injury deaths due to nonvehicular accidents (e.g., fires, drownings) is higher among black adolescents than among white adolescents (71). Suicide rates among black adolescents have traditionally been much lower than suicide rates among white adolescents, in spite of blacks' "obvious exposure to greater external stresses of discrimination, poverty, and marginal minority status in American society" (71). What sociocultural factors account for this phenomenon are not known, although it has been suggested that protective factors may have been provided by five institutions (family, church, fraternal and social organizations, community schools, and extended kin and social support networks) which characterized the traditionally segregated black community (71).

Mortality rates are only one indicator of adolescents' health status. As noted elsewhere in this report, a broad definition of adolescent health could include aspects of traditional definitions of health (i.e., the presence or absence of physical disease or disability); adolescent problem behaviors (e.g., delinquency, drug use, sexual activity); positive components of health (e.g., social competence); health and well-being from the perspective of adolescents themselves; and social influences on health (e.g., families, schools, communities, policies).[50] But, as noted earlier, reliable population-based information about black adolescents' health status is lacking. Overall, a number of analyses have shown that black adolescents—especially poor black adolescents living in central cities—appear to be at higher risk than white adolescents for many health problems (33,71, 149).

As discussed elsewhere in this report, arrest rates for serious offenses, particularly serious violent offenses, are much higher for black adolescents than for white adolescents, and black adolescents are disproportionately represented in juvenile justice facilities (253,257).[51] In 1987, the arrest rate for serious violent offenses was about six times higher for black adolescents than for white adolescents (253). One explanation for the racial disparity in arrest rates is that crime rates are strongly associated with low socioeconomic levels and urban location, and both of these factors impinge more profoundly on black youth. Statistics comparing racial groups do not typically control for such demographic factors. A second explanation for the racial disparity is that blacks adolescents are more likely to be arrested than whites engaged in the same behavior (90). When self-reports of offenses are examined, racial disparities are much smaller than those typically reported in arrest statistics (51,105). A third explanation for the racial disparity in arrest and incarceration rates is that antisocial behavior in white adolescents is more likely to be interpreted as an indicator of emotional disturbance and treated as such, whereas black adolescents are more typically referred to the juvenile justice system rather than the mental health system (19,46).

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[49] For further discussion of homicide rates among black adolescents, see ch. 13, "Delinquency: Prevention and Services," in Vol. II.

[50] See box A in Vol. I, "Summary and Policy Options."

There are significant differences between black and white adolescents in sexual activity, pregnancy, abortion, and childbearing rates. Black adolescents, many of whom are from socioeconomically disadvantaged families, tend to initiate sexual activity at an earlier age, are less likely to use contraceptives, are more likely to experience out-of-wedlock births, and are less likely to have an abortion. Researchers disagree on the relative importance of socioeconomic status and other factors in accounting for these racial differences.[52] In any event, it has been estimated that 40 percent of all black females become mothers before the age of 20; nearly 90 percent of those births are to single mothers (111,140).

As discussed elsewhere in this report, black adolescent females are at particularly high risk of experiencing iron-deficiency anemia (60) and obesity.[53]

As noted elsewhere in this report, adolescents who engage in sexual intercourse are at risk of infection with human immunodeficiency virus (HIV) or other sexually transmitted diseases (STD). Through August 1990, black adolescents accounted for 36 percent of the 568 AIDS cases among U.S. adolescents ages 13 to 19 (236a).[54]

Hispanic Adolescents—In general, data on the health of Hispanic adolescents are limited (260). The Hispanic Health and Nutrition Examination Survey (HANES), a special population survey conducted in 1982-84 by the National Center for Health Statistics in DHHS, found that Mexican-American adolescents may experience higher rates of obesity, increasing their risk of eventually developing Type II (adult-onset) diabetes (138,260).

Higher arrest rates for drunkenness have been found for some Hispanic adolescents in comparison with white adolescents, and inhalant abuse is a significant problem for Mexican-American adolescents, especially those living in inner cities (163,169).

High school dropout rates among Hispanic adolescents are high; as many as 45 percent of Mexican-American adolescents drop out in some areas (37,82). In 1989, 33 percent of Hispanics ages 16 to 24 were high school dropouts (211a).[55]

There are few data on mental disorders among Hispanic adolescents (175). Nonetheless, there is some evidence that Mexican-American adolescents (but not other Hispanics) report higher levels of depression than whites or blacks (175,260).

In 1980, the overall birth rate for Hispanic adolescents (all races) was about double the rate for non-Hispanic white adolescents and about four-fifths the rate for non-Hispanic black adolescents (192). Through August 1990, Hispanic adolescents (all races) accounted for 18 percent of the 568 AIDS cases among U.S. adolescents ages 13 to 19 (236a).[56]

Asian Adolescents—Information concerning the health status of Asian and Asian-American adolescents is quite limited. Asians and Asian-Americans tend to have diets that are high in sodium, possibly increasing their eventual risk of heart disease (35,41). In addition, because Asians may have difficulty maintaining traditional dietary patterns that include sources of calcium not readily available in the United States, their low use of dairy products results in low calcium intake (99,190).

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[51] See ch. 13, "Delinquency: Prevention and Services," in Vol. II.

[52] See ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II for further discussion.

[53] See ch. 7, "Nutrition and Fitness Problems: Prevention and Services," in Vol. II.

[54] See ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services," in Vol. II for further discussion.

[55] For a further discussion of dropout rates, see ch. 4, "Schools and Discretionary Time," in Vol. II.

[56] See ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services," in Vol. II for further discussion.

As noted earlier, a systematic national epidemiologic study of mental health problem U.S. adolescents has not been conducted. Asian adolescent refugees have been found to suffer from depressive disorders and a delayed onset of chronic post-traumatic stress disorder syndrome (20). One study indicated that a third of Vietnamese teenage refugees in foster care had experienced clinical depression during their first 18 months in the United States (20). A study of adolescent and young adult Vietnamese refugees in the Philippine Refugee Processing Center prior to their resettlement in the United States indicates that adolescents (ages not specified) who had been in the resettlement camp longer than 3 years scored higher on a depression measure and a psychological symptom checklist than those without camp experience (94).

Asian refugees are also at particularly high risk of experiencing problems such as tuberculosis (122). Health examinations of 80 Indochinese (Cambodian, Vietnamese, or Laotian) adolescent refugees ages 11 to 19 indicated that half had positive tests for tuberculosis, 38 percent had incomplete immunizations, a third tested positive for parasites, and 14 percent tested positive for hepatitis B (62).

American Indian and Alaska Native Adolescents—A 1986 OTA report entitled *Indian Health Care* found that in almost every Indian Health Service area and on almost every health indicator, the health of American Indians is poorer than that of the U.S. population in general (199).

Studies have found that, although rates vary across tribes, American Indian and Alaska Native adolescents are at increased risk of experiencing mental health problems such as low self-esteem, alienation, depression; they also have high rates of suicide, alcohol and substance abuse, and running away from home (109,112,128,136,202). American Indian adolescents are at high risk of having been physically or sexually abused (202).

Because of the high rates of alcoholism among American Indians, Indian adolescents are at increased risk of having been born with fetal alcohol syndrome (202) High rates of childhood otitis media (ear infections) lead to higher rates of hearing impairment (136,202). Developmental disabilities, such as mental retardation and learning disabilities, occur at higher rates in American Indian and Alaska Native children than in white children (159,172,202).

Mortality due to accidental injuries among American Indian adolescents is high. As discussed elsewhere in this report, American Indian adolescents experience death from accidental injury at nearly twice the rate of black or white adolescents (22).[57] One explanation for this is that Indian adolescents have high rates of drinking and driving (45). In addition, because many of them live in rural areas, Indians are less likely to have speedy access to trauma centers. Road and vehicle conditions have also been mentioned as factors contributing to serious injuries among Indians of all ages.

Nutritious traditional dietary patterns of American Indian communities have generally been lost with increasing contact with non-Indians (22). American Indian adolescents are more likely than non-Indian adolescents to be overweight and to eventually experience and die from adult-onset diabetes (22).

The prevalence of untreated dental disease among American Indian adolescents is high (22). In 1983-84, the Indian Health Service of DHHS conducted a service-wide study of children and found that overall, American Indian children have twice the amount of dental caries as the national average (248). It also found that by the end of adolescence, two out of five young American Indian patients have destructive periodontal disease with bone loss.

In 1986, almost a quarter of the births to American Indians were to females younger than age 20; the adolescent fertility rate appears to be rising, although there is substantial variation across tribes (22).

Native Hawaiian Adolescents—There are more than 200,000 persons of Hawaiian ancestry, or Native Hawaiians, residing in the State of Hawaii, and they comprise nearly 20 percent of the State's population (139).[58] The Native Hawaiian population is young and growing, and the Native Hawaiian adolescent population in Hawaii is among the largest ethnic grouping. In 1986, 22 percent of the Native Hawaiian population (an estimated 44,000 individuals) were between the ages of 10 and 18, and 24 percent were ages 9 or younger (139). While there are clusters of predominantly Native Hawaiian communities in Hawaii, the Native Hawaiian population of Hawaii is distributed throughout the islands of Hawaii (139). Native Hawaiians are more likely than other ethnic groups in Hawaii to be poor and are also more likely to receive public assistance (139).

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[57] See ch. 5, "Accidental Injuries: Prevention and Services," in Vol. II.

A number of health and related problems particularly affecting Native Hawaiians have been identified by various surveys by the State of Hawaii Department of Health, although adolescent-specific data are scarce (139). Native Hawaiian students persistently perform below statewide averages on standardized achievement tests, and their performance relative to other ethnic groups worsens in the higher grades (75a). Compared to all other State students, a much lower percentage of Native Hawaiian students receive some college education (40 percent versus only 20 percent) (166a). Hearing impairments among Native Hawaiian children, most likely from untreated middle ear infections, have been recognized as a major problem and a probable contributor to poor school performance (139). State of Hawaii Health Department surveys find that other impairments can also be found at relatively high rates among Native Hawaiian children and adolescents ages 5 to 17 (vision, back and spine, upper-extremity/hip), with only Caucasians in Hawaii having higher rates overall and for most categories (139). Native Hawaiians have the highest rate of obesity among ethnic groups in Hawaii, putting them at higher risk of developing Type II diabetes (251).

Native Hawaiian adolesents are more likely than adolescents in other ethnic groups in Hawaii to give birth: in 1987, 5.9 percent of total Native Hawaiian births were to mothers 17 or younger, compared to 2.1 percent for all other ethnic groups combined (77).

Hawaii has examined its adolescent population in relation to delinquent acts and found a disproportionate incidence of arrests among Native Hawaiians who account for 35 percent of all arrests among individuals under age 18 (139).

On the positive side, Native Hawaiian children are more likely than non-Native Hawaiian children to live in family households (139). Among those family systems that build on strong Hawaiian traditions, common characteristics include multiple parenting within an 'ohana (extended family), early indulgence followed by a shift at 2 to 3 years of age to a primarily peer-directed socialization experience, socialization toward a group- and family-oriented values system, and learning experiences that emphasize modeling and mutual participation rather than verbal interaction. Some of the typically Hawaiian values (e.g., cooperation over aggressive individualism) are diametrically opposed to Western cultural characteristics for success in many areas (e.g., education, business) (139). Further, it may be important to note that Hawaiian concepts of health differ from "Western" or mainstream U.S. concepts (139). Hawaiian cultural concepts of health are more holistic than Western concepts and include physical and spiritual states (76). There is no word, for example, for "mental" health or illness (76). This broader conceptualization has had an impact on the delivery of some prevention interventions to Native Hawaiian adolescents (139). However, extensive intermarriage with other ethnic groups has produced a wide variety of beliefs, childrearing patterns, and other practices among Native Hawaiians.

Access to Health Services by Racial and Ethnic Minority Adolescents

Patterns of Health Care Utilization by Racial and Ethnic Minority Adolescents

Information on the utilization of mainstream health services by racial and ethnic minority adolescents is quite limited. Even for adult populations, data on the utilization of health services are quite limited, as national surveys have generally not sampled enough individuals from ethnic or racial minority groups to provide meaningful data. As noted earlier, racial and ethnic minority persons disproportionately live in poverty, and many of them experience financial barriers to the utilization of health care. In addition, some of them experience geographic or other nonfinancial (e.g., cultural) barriers to the utilization of services.

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[58] Because of the small number of Native Hawaiians living elsewhere in the United States, and because almost all information about Native Hawaiian health status and specialized health services is from sources in the State of Hawaii (139), this discussion of Native Hawaiian adolescents is limited to such adolescents living in the State of Hawaii. According to data from the U.S. Census, 69 percent of all Native Hawaiians living in the U.S. live in Hawaii (139). For purposes of this chapter, in Federal statutes, and for most analyses by the U.S. Department of Commerce, Bureau of the Census, and the Hawaii State Department of Health Health Surveillance Program, a Native Hawaiian is a person of either partial or sole Hawaiian ancestry (139). However, less than 5 percent of the Native Hawaiians are pure Hawaiians, and probably two-thirds would identify themselves as primarily Native Hawaiians, rether than primarily some other ethnic group (139).

Information from a variety of sources, while extremely limited, suggests that the utilization of mainstream health-related services tends to be lower among black and Hispanic adolescents than among white, non-Hispanic adolescents. Black children and adolescents, for example, may be less likely than whites to receive preventive care or appropriate medical services (239). A study of Job Corps participants ages 16 to 22, all of whom were low income, found that blacks were more likely than whites or Mexican Americans to have incomplete immunizations (57 percent of blacks v. 42 percent of Mexican Americans and 51 percent of whites) (61). The National Health Interview Surveys for the years 1985 through 1987 found that blacks under 18 years of age were far less likely than whites of that age to have had a physician contact (239). More disturbing, this was particularly true if they were in fair or poor (as opposed to good to excellent) health (239).[59] These surveys also found that the only large black-white differences in rate of annual physician contacts was for individuals under 18. Blacks under age 18 had about 2.8 physician contracts per person per year, while whites under age 18 had 4.5 physician contacts per person per year (239).

Nearly one-fourth of the Mexican-American adolescents ages 12 to 17 who were surveyed in the Hispanic HANES in 1982-84 reported having no regular source of health care; one-fifth reported that they had not seen a physician within the past 5 years, and about one-third reported that they had not had a preventive care visit within 5 years (138). Some evidence suggests that less acculturated Mexican Americans are less likely than more acculturated Mexican Americans to use outpatient care for physical or mental health problems. These differences persist even when socioeconomic status is controlled for (267).

Although the population surveyed was not adolescent, it is interesting that one national survey by Louis Harris and Associates found that blacks and Hispanics were less likely to report being completely satisfied with the most recent medical visit on five out of seven measures: travel time, time with physician, information received, quality, and the overall medical visit (11).[60] Similarly, black and Hispanic adults reported more "special access problems" (e.g., in obtaining health insurance and obtaining and financing care for serious illness and emergencies) than did whites (11). The research group that analyzed the survey results suggested that racial and ethnic minorities were experiencing particular difficulties and barriers in obtaining needed health care services, despite the considerable improvements in access they experienced as the result of policy and program changes in the 1960s and 1970s (11).

Adults from some minority groups use informal helping networks (e.g. families, folk healers) to address health problems, although the extent to which racial and ethnic minority adolescents use these networks is not generally known (17). Asian adults with emotional difficulties, for example, often turn to their families for help and turn to outside agencies as a last resort (188). Alternatives to mainstream health services used by Asian-American adults for health problems include herbal medicines, acupuncture, and diet and exercise regimens (189). Whether Asian-American adolescents use these strategies is unknown. Native Hawaiians in general appear to make widespread use of informal sources of care, although the actual level of use of these sources of care by Native Hawaiian adolescents is not known (139).[61]

For the most part, it appears that racial and ethnic minority adolescents who do obtain health and health-related services obtain them through the mainstream service system (44). The use of alternative health systems among Mexican-American adolescents is apparently limited; only 2 percent of Mexican-American adolescents surveyed in the Hispanic HANES reported using a folk healer in the past year (138).

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[59] White children under age 18 in fair or poor health had an average of 15.5 physician contacts per year, compared to 6.5 physician contacts per year for black children in fair or poor health (239). Survey data were not given separately for 10- to 18-year-olds; thus, it is not clear whether differences existed between younger children and adolescents.

[60] Levels of satisfaction were similar for office waiting time and out-of-pocket cost (11).

[61] While the State of Hawaii is diligent about collecting health status data on an ethnic basis, the issue of health and related services specifically for Native Hawaiians is a relatively recent policy issue and there have been few quantitative analyses of services to Native Hawaiians (139).

Services and interventions that address linguistic, geographic, economic, and cultural barriers (44,98,167) to the utilization of services are likely to improve racial and ethnic minority adolescents' access. It is likely that it is quite important for services to be in the neighborhoods where minorities reside, be provided in the language spoken by the adolescent and his or her family, be financially affordable, and be responsive to the cultural background of the adolescent (44).

Services and Interventions To Increase Access to Health Services Among Racial and Ethnic Minority Adolescents

As noted earlier, a disappropriate number of racial and ethnic minority adolescents are poor or near-poor, and they confront many the same financial and other barriers to access other poor adolescents do. For these adolescents, the expansion of health insurance coverage or the establishment of school-linked or community-based health centers may effectively improve access to services.[62] A question that arises, however, is whether racial and ethnic minority adolescents have special needs for services that cannot be effectively met in the "mainstream" system. More research on this topic would be useful. There is an increasing consensus, however, that services for racial and ethnic minority individuals, including children and adolescents, would be improved if they were "culturally competent."

LATIN AMERICAN YOUTH CENTER

Photo credit: Office of Technology Assessment

Services that address linguistic, geographic, economic, and cultural barriers to utilization are likely to improve racial and ethnic minority adolescents' access to needed services. The Latin American Youth Center provides a broad range of services, as well as a place to "hang out," for young people in a Washington, DC, neighborhood populated by large numbers of immigrants from Central America.

Culturally competent services for adolescents may be difficult to design, because there is little systematic information about how racial and ethnic minority adolescents experience adolescence. There is beginning to be some systematic analysis of what a culturally competent system of care is, but the knowledge base has not yet been applied systematically to the design of training programs for health care and other service providers. Overall, there is little systematic description of how services have been developed or adapted to meet the specific needs of racial and ethnic minority adolescents, and even less scientific evaluation of the effectiveness of available services. Currently, however, minority providers and providers trained to be sensitive to the sociocultural aspects of providing health care are few (6,17,44).

Developing Culturally Competent Systems of Care—The concept of a "culturally competent system of care" has been suggested as a model for working effectively in cross-cultural situations (44, 202). Several characteristics are said to be necessary for a system to be considered culturally competent

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[62] For a discussion of school-linked health centers and other innovations in the delivery of health and related services to adolescents, see Ch. 15, "Major Issues Pertaining to the Delivery of Primary and Comprehensive Services to Adolescents," in this volume.

(44). The system must value diversity at all levels, have a sense of its own culture, be aware of the dynamics involved when cultures interact, have institutionalized cultural knowledge, and have developed adaptations to diversity. A culturally competent system of care recognizes and values cultural diversity, and works effectively with the natural support and helping networks within minority communities. Effective providers must be sensitive to cultural differences within as well as across racial and ethnic groups.

There is some evidence that, when given the choice, black adults prefer to be seen by a black provider (6). Black or other racial and ethnic minority adolescents may similarly prefer to have access to minority providers, although information on this topic is scarce. Currently, there are few minority providers in the health professions. Between 1980 and 1987, only 11 percent of doctoral degrees in health education earned were awarded to minorities; half of them went to blacks (6). In 1987, blacks made up only 5.2 percent of medical school graduates (181). A recent report by a DHHS task force recommended the recruitment and training of more minority doctors (227) and a new law passed in the 101st Congress (Public Law 101-527) will provide additional scholarships and loans to minority students.

According to some observers, however, not all minority providers can be assured to be culturally competent. Some racial and ethnic minority doctors trained in major medical schools have the same attitudes and values as their white peers (71), and changes in the health care field have made individual practice in low-income areas less attractive. Further, while members of broad racial and ethnic minority groups (e.g., Asians, Hispanics) may have some things in common with other members of that group, the cultural differences of subgroups may prove more important. An Asian health care provider of Japanese heritage, for example, will not necessarily be competent to deal with a Hmong adolescent from Southeast Asia. Perhaps the most well-recognized need is for the cross-cultural training among white health professionals, who are often ignorant of the dynamics and interpretations of the behavior of racial and ethnic minority adolescents (8,123).

Considerations in Developing Services for Racial and Ethnic Minority Adolescents—Many studies have found that blacks, Asian Americans, Hispanics, American Indians, and Native Hawaiians strongly value the family (23,63,72,80,92,113,118, 135,169,186,265,270). Thus, services that include the family may very well be most effective. For Asian-American adolescents, services that gain family involvement, use supportive family networks, and promote family decisionmaking are believed likely to be more effective, although there have been no tests of this model (118,277). Attempts to involve parents may pose practical difficulties for single-parent households, however, and some adolescents report that they prefer that parental involvement be an option rather than a requirement (47,201). For black adolescents, particularly those in single-parent households, family involvement may include using a total kinship network composed of persons related by blood, marriage, friendship, neighboring residence, or work association (96). When providing services to Hispanic adolescents and their families, it may be important to respect the traditional family age and sex hierarchies of power (169), although this too may pose problems for the adolescent clients. Although churches have been identified as important community resources, especially for black adolescents, some observers believe that churches may not be appropriate or willing sources of health information, particularly regarding issues related to sexuality or drug use (47). When willing, they may not have the necessary staff, funds, or technical expertise (161).

Level of acculturation is another important variable to consider when developing interventions and services for adolescents (e.g., 88,169). Normal conflict between adolescents and older generations in the family may be exacerbated by culture conflicts, when more "acculturated" adolescents do not wish to follow traditional practices (118,189). For example, there can be conflict between an Hispanic-American adolescent girl and her traditional grandmother when the adolescent wishes to experience the same freedom to go on unchaperoned dates as her peers. Three primary sources of intergenerational conflict for Southeast Asian refugee adolescents have been identified: conflicts concerning pressure for the adolescents to date and marry within their ethnic group; conflicts concerning career choices, with adolescents experiencing pressure to pursue professional careers; and conflicts caused by role reversal, for example when an adolescent assumes greater familial responsibilities because he or she has the language proficiency to interact more effectively in the outside world (118).

Effectiveness of Programs Targeting Racial and Ethnic Minority Adolescents—Information on programs geared to the delivery of health and related services to racial and ethnic minority adolescents is severely limited. Several models of programs designed to serve racial and ethnic minority adolescents have emerged, but few of these have been evaluated. Thus, it is difficult to draw conclusions about which are the best models for delivering services to ethnic and racial minority adolescents. Much of the information about the effectiveness of such models is anecdotal information based on the experiences of providers rather than scientific evidence.

Some programs aim to increase the self-esteem of minority adolescents by providing ethnic role models or mentors. One such program is Project IMAGE, a church-based program in Chicago that pairs young black males ages 8 to 18 with volunteer black men in an effort to provide a positive force for the youth and to link them with special services and programs (168). Another program, the Las Madrinas (Godmothers) program administered by Hacer, Inc., in New York City, pairs low-income Hispanic girls at risk of dropping out of school with young Hispanic professional women who act as volunteer mentors (83). The goal of this program is to promote leadership among the girls and encourage them to stay in school. Activities include workshops, referrals to services, and field trips to cultural, educational, and recreational sites.

One program that has been evaluated used short stories about well-known Puerto Rican men and women who had overcome adversity (heroes) to emphasize the importance of cultural identity and foster the development of self-esteem and coping skills among Puerto Rican adolescents having trouble in school (42,43). An evaluation of this program indicated that Puerto Rican adolescents who participated in the program experienced increased ethnic identity and reduced anxiety compared with similar adolescents randomly assigned to a control group. Interestingly, the intervention had somewhat negative effects on ethnic identity and self-esteem for adolescents in families headed by two biological parents, as opposed to mother-headed single-parent households (43).

Another approach to the promotion of health and well-being among racial and ethnic minority adolescents is to instill a sense of cultural awareness by involving adolescents in culturally traditional ceremonies. The use of interventions incorporating Afrocentric rites of passage for adolescents is an example of this approach (44). Programs incorporating Afrocentric rites of passage are intended to support the transition of black adolescents into responsible adult roles (50). Many traditional American Indian health practices are gradually being incorporated by tribes and "Western" mental health providers into contemporary approaches to mental health treatment for Indian adolescents. These include the "four circles," sweat lodge, and "talking circle," which are treatment strategies based on traditional healing practices (112,202).

Information about the effectiveness of mentoring and modeling programs for racial and ethnic minority adolescents is generally lacking. However, Project EPIC (Education and Prevention in Communities) at Wayne State University in Michigan is developing an evaluation to assess the effectiveness of rites of passage programs in reducing substance abuse among adolescents (264).

Hawaii currently offers a wide range of services for adolescents (194,262). Although culturally appropriate services targeted specifically to Native Hawaiian adolescents are few and have not been evaluated for effectiveness, the number of services for Native Hawaiian adolescents is increasing (139). The Native Hawaiian Health Care Act of 1988 (Public Law 100-579) will lead to the eventual establishment of Native Hawaiian health systems throughout the State that will provide health promotion, disease prevention, and primary care services (139). The implementation of this act provides a critical opportunity to target services for Native Hawaiian adolescents.

Major Federal Programs Pertaining to Racial and Ethnic Minority Adolescents

The Federal programs to help low-income persons discussed earlier in this chapter tend to serve many minority persons because of the disproportionate number of minorities who live in poverty. The discussion here focuses on Federal programs that are concerned specifically with serving racial and ethnic minority populations.

Many of the programs are within DHHS, but the U.S. Department of Education, the U.S. Department of Agriculture, and the U.S. Department of Justice also have some programs. In addition to the programs discussed here, there are isolated examples of federally funded grants that focus on meeting the health needs of minority adolescents. There are also programs that focus on other needs of minority adolescents, such as education or job training.

U.S. Department of Health and Human Services

Three of the four major components of DHHS mentioned earlier—the Family Support Administration, and the Office of Human Development Services, and the Public Health Service—have programs that focus specifically on racial and ethnic minority populations. The Health Care Financing Administration does not focus specifically on these populations.

Family Support Administration (FSA)—FSA's *Office of Refugee Resettlement* provides Federal funds to States for refugee and entrant assistance programs (213). Refugee and entrant assistance programs were established in 1980 in order to assist refugees and Cuban and Haitian entrants in becoming employed, self-sufficient, and assimilated into U.S. society as soon as possible after their arrival (213). Federal funds are provided to help offset necessary costs, although most funds are used to provide grants to States for refugee assistance and services by way of cash assistance, medical assistance, State administrative costs, social services, and targeted assistance. The amount of assistance provided specifically to adolescent refugees or their families is not available.

One program of the Office of Refugee Resettlement that has a substantial impact on adolescents is in the Unaccompanied Minor Refugee Program which provides support for unaccompanied refugee minors (216). The U.S. Catholic Conference and Lutheran Immigration and Refugee Service help the Office of Refugee Resettlement place unaccompanied refugee minors in licensed child welfare programs (e.g., foster care, group care, independent living, residential care), and costs incurred on their behalf are reimbursed by the Office of Refugee Resettlement until a month after the minor's 18th birthday.[63] Since 1979, more than 8,500 unaccompanied minor refugees have entered this program. Nearly half of these minors who enter the program continue to be under its jurisdiction through their adolescence. There are now about 3,000 unaccompanied refugee minors in care.

Another program of the Office of Refugee Resettlement is the Transition Program for Refugee Children. This program provides funds for the special educational needs of refugee children and adolescents, including bilingual education, remedial programs, school counseling and guidance services, and instruction to improve English language skills. Support is also provided for training for parents, and in-service training to educational personnel (216).

Under the Immigration Reform and Control Act of 1986 (Public Law 99-603), the Office of Refugee Resettlement provides Federal grants to States for the purpose of helping State and local governments defray expenses incurred in providing public assistance, public health assistance, and educational assistance to eligible legalized aliens. These grants are called "legalization assistance impact grants." States may use the grants for educational services for legalized alien children and adolescents who have been in the United States for less than 3 years and who reside in school districts with large concentrations of eligible legalized aliens (217). Although $898.5 million was available to States under this grant program in fiscal year 1989, and adolescents were eligible for services, the amount of such assistance specific to adolescent immigrants is not available from the Federal Government.

Office of Human Development Services (OHDS)—OHDS oversees a number of programs related to racial and ethnic minority populations.

OHDS' *Administration for Children, Youth, and Families* makes funds available through its Family and Youth Services Bureau for programs to prevent substance abuse among runaway and homeless Native American adolescents. Projects are expected to incorporate Indian tribal values and languages, and develop a positive cultural and family identity (54 FR 15092-15106).

OHDS' *Administration for Native Americans* provides training and technical assistance to assist public and private Native American organizations in developing, conducting, and administering projects to carry out locally determined social and economic development strategies (223). In recent years, the Administration for Native Americans has targeted the problem of drug and alcohol abuse prevention. In fiscal year 1989, OHDS used its coordinated Discretionary Funds program to allocate about $250,000 to a total of five projects in this area. Not all of the projects were adolescent-specific.

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[63] States may permit support to extend for longer periods (216).

OHDS used its Coordinated Discretionary Funds Program for fiscal year 1989 to make funds available for prevention and treatment of alcohol abuse among minority youth using culturally sensitive interventions; for the prevention and treatment of alcohol abuse among Native American adolescents using runaway and homeless youth centers; and for innovative community approaches to entrepreneurial activity with Native American adolescents (53 FR 33686-33722).

Through interagency agreements with the Indian Health Service and the Bureau of Indian Affairs, the Administration for Native Americans has also funded health promotion activities, including alcohol and drug abuse prevention education. In 1989, the Administration for Native Americans transferred $70,000 to the Bureau of Indian Affairs for a health education program expected to involve 27,000 students attending Bureau of Indian Affairs schools (223). In the past, OHDS has used its discretionary funds to fund projects to increase minority access to runaway and homeless youth center services; prevent child abuse among minorities; reunite American Indian families with children separated because of parental substance abuse; and prevent substance abuse among Native American adolescents. OHDS has also funded programs to increase the participation of historically black colleges and universities and Native American organizations in OHDS' funding opportunities (221).

OHDS also provides funds to increase the number of minorities entering the field of social work to do work in the area of child welfare. Funds are provided for traineeships and in-service training to historically black colleges and universities and to colleges controlled by Indian tribes or serving Indian reservations.

Public Health Service (PHS)—PHS has a number of agencies with programs that address the health needs of racial and ethnic minority adolescents:

- the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA);
- the Health Resources and Services Administration (HRSA);
- the Indian Health Service (IHS); and
- the Office of Minority Health.

Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA)—ADAMHA consists of three agencies concerned with mental health and with substance abuse:

- the National Institute on Drug Abuse,
- the National Institute of Mental Health, and
- the Office of Substance Abuse Prevention.[64]

ADAMHA's *National Institute on Drug Abuse* has several initiatives related to substance abuse among minority adolescents. Most of the projects focus on epidemiology and risk factors; fewer focus on prevention or specific treatment approaches.[65] Projects include several studies examining the effects of drug use on school dropout rates in minority communities, a study examining the etiology of substance abuse among high-risk black adolescents, and a study of cultural factors affecting vulnerabilities to substance abuse among Hispanic adolescents (229,230).

The National Institute on Drug Abuse also conducts the National Household Survey on Drug Abuse, a periodic national prevalence survey of drug use. The survey oversamples person ages 12 to 34, blacks, and Hispanics, but still has a very small sample of nonwhite adolescents.

The National Institute on Drug Abuse has Special Populations Research and Training Programs that work to enhance research and training opportunities for minority researchers. Technical assistance is provided to potential researchers to develop their grant writing and research skills (230).

ADAMHA's *National Institute of Mental Health* administers the Child and Adolescent Service System Program (CASSP), a small grant program established in 1984 to develop new initiatives to improve the delivery of mental health services to severely emotionally disturbed children and adolescents (231). CASSP is aimed at improving coordination among the child welfare, juvenile justice, mental health, and special education systems (71). It provides technical assistance and acts as a clearinghouse for research information to CASSP grantees, and provides funding for grants to States.[66] As of June 1989, CASSP had been funded in 42 States (231). Fiscal year 1989 funding for CASSP was $9.8 million.

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[64] Basic activities of ADAMHA agencies focusing on alcohol and drug abuse are described in ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II. Activities of the National Institute of Mental Health, the ADAMHA agency focusing on mental health, are described in ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II. Basic ADAMHA activities in the context of the entire Federal role in adolescent health are described in ch. 19, "The Role of Federal Agencies in Adolescent Health," in this volume.

[65] Most Federal drug abuse prevention activities relevant to minority adolescents take place in the Office of Substance Abuse Prevention (see below).

A major goal of CASSP is to ensure that services to severely emotionally disturbed children and adolescents from racial and ethnic minorities are sensitive to cultural differences. In 1986, CASSP sponsored a workshop on the development of mental health programs for minority children and adolescents and their families. Following that workshop, CASSP project directors were instructed to develop at least one major goal related to improving services for cultural and ethnic minority children and adolescents in their States; each State receiving a CASSP grant is required to develop a minority objective. State efforts include such activities as developing training programs in cultural issues for service providers, establishing task forces to explore the difficulties that minority children and adolescents have in gaining access to existing mental health services and to advise in the implementation of minority objectives, and making outreach efforts to involve minorities in CASSP activities (231). Technical assistance is available through CASSP to help develop and implement minority objectives (e.g., 44).

The National Institute of Mental Health funds six centers that do research and provide treatment targeted to the needs of particular ethnic groups (84a). It recently awarded $1.4 million for a new Research Center on the Psychobiology of Ethnicity that will investigate, among other things, ethnic differences in how people respond to drugs for mental disorders, "culture-bound syndromes," and how different groups conceptualize psychiatric disorders (84a). How much of a focus will be on adolescents is unknown.

ADAMHA's *Office of Substance Abuse Prevention* was created in 1986 to provide national leadership for alcohol and drug abuse prevention (234). The Office of Substance Abuse Prevention has a demonstration grant program with a strong focus on minority and multicultural adolescents. Of the 130 demonstration grants awarded in 1987 (most of which target adolescents), 56 percent are targeted at minority groups. Of these, 24 programs focus on blacks, 15 on Hispanics, 12 on American Indians and Alaska Natives, 6 on Asian Americans and Pacific Islanders, and 16 on multiethnic minority groups. Most of the remaining grants are for multiethnic projects that include whites. Many of the projects incorporate strategies to enhance their cultural competence, such as involving respected community members in the program, recruiting minority staff at all levels, encouraging the use of traditional cultural activities (e.g., celebrating cultural festivals or teaching traditional languages), and using culturally appropriate media and messages in drug and alcohol education efforts.

Health Resources and Services Administration (HRSA)—As noted earlier, HRSA's *Bureau of Maternal and Child Health* (formerly the Office of Maternal and Child Health) administers the maternal and child health block grant programs authorized by Title V of the Social Security Act. In administering this program, the Bureau seeks to remove cultural, communication, and systems barriers to health services for medically underserved women, infants, and children, many of whom belong to minority groups (91). The Bureau has established a Workgroup on Culturally Distinct Populations to provide advice on the best use of grant money to improve health care for minorities.

As noted earlier, the Bureau of Maternal and Child Health sets aside 15 percent of Federal maternal and child health block grant funds to support special projects of regional and national significance (SPRANS) which contribute to the health of mothers and children with special needs. A number of the projects that have been funded focus on improving the provision of health services to minority and poor adolescents (91). Examples include a project to reduce teenage pregnancy among black adolescent girls, a project to prevent injuries among American Indian adolescents, and a project to promote the health of American Samoan adolescents (91,151,244).

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[66] See ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II for further discussion of CASSP.

HRSA's *Bureau of Health Professions* and *Bureau of Health Care Delivery and Assistance* support a variety of personnel training programs. The Division of Disadvantaged Assistance in the Bureau of Health Professions administers a Health Careers Opportunity Program, which provides assistance to health profession training programs that serve minorities and other disadvantaged persons to facilitate the recruitment and retention of minorities in health professions; about 13,000 students take part in programs of the Health Careers Opportunity Program annually (240a). The program also provides direct financial assistance to disadvantaged students.

In fiscal year 1988, HRSA began providing awards through its "Excellence in Minority Health Education Program" to historically black colleges and universities to strengthen their capacity to train minority students in health professions (240a). Personnel from the National Health Service Corps, who staff community and regional health centers, receive orientation about linguistic and cultural aspects of health care (240a).

Indian Health Service (IHS)—The IHS provides health services to American Indians and Alaska Natives (199,202). IHS clinical facilities have generally been placed on or near reservations (199). About half of American Indian adolescents reside on reservations and are eligible for health care services through the IHS (202).

The IHS funds three regional adolescent treatment centers for substance abuse rehabilitation through its Alcohol and Substance Abuse Programs Branch (249). The IHS also provides partial funding for teen centers in or near four Albuquerque area schools, and health services at Bureau of Indian Affairs boarding schools (22). In addition, the IHS has made youth a priority for its prevention programs, planning to specifically emphasize teen pregnancy, alcohol and drug abuse, mental health, violence, and suicide.

Unfortunately, however, numerous factors make the provision of health services to Indian adolescents inadequate, even for reservation-based Indian adolescents. In recent years, overall IHS funding has just kept pace with inflation with no real increases (48). Most IHS funds are used to provide acute care to Indians of all ages; except for some funding for substance abuse services, teen pregnancy services and participation in several multifunded adolescent health centers in Albuquerque, New Mexico (45), there is no targeted treatment funding for adolescents. Little money is available for prevention services (48). Although the IHS has a Maternal and Child Health Program, it is merely advisory and has no budget of its own to implement programs. Similarly, although the IHS policy recognizes that adolescents have special needs in health care, and youth are a priority, adolescent clinics have not been established as part of the usual IHS health care delivery system, and there are no adolescent medicine specialists in the IHS (22).

Confidentiality is often important to adolescents considering the use of health care services[67] (201). Various aspects of IHS delivery may result in a lack of privacy for American Indian and Alaska Native adolescents, and the lack of privacy may reduce such adolescents' willingness to seek appropriate health care (22). For example, especially in small communities, the IHS is a major employer of members of local tribes. Research on this or other nonfinancial factors affecting access to care for American Indian adolescents is nearly nonexistent.

Office of Minority Health—The *Office of Minority Health* was created within the DHHS Office of the Assistant Secretary of Health in 1985 to address the problems and implement the recommendations of the Secretary's Task Force on Black and Minority Health (164). These recommendations included stimulating the development of innovative programs to improve the health status of minority populations and advocating a national strategy to address the health needs of minorities (164,227).

The Office of Minority Health has developed a research center to investigate minority health problems (164). The Office of Minority Health has also provided funding for a number of demonstration grants for the development of community health coalitions to reduce risk factors among minority populations (252). Funded projects include programs designed to reduce teenage pregnancy; reduce the risk of alcohol and other drug problems among high-risk, urban Latino youth; and provide AIDS education to American Indian high school students and adults using Native healing principles and techniques. Additional HIV education and prevention programs directed at black and Hispanic adolescents and adults have also been funded (25,252) as has a special initiative on minority males (54 FR 22312).

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[67] See ch. 17, "Consent and Confidentiality in Adolescent Health Care Decisionmaking," in this volume.

Although the overall goal of the Office of Minority Health is to improve the health status of blacks, Hispanics, Asian-Americans, Pacific Islanders, and Native Americans, the U.S. General Accounting Office recently reported that the office "does not have specific goals or objectives for each of these groups, nor does it have short- and long-term strategic plans for its objectives" (194a). Later in 1990, the potential role of the Office of Minority Health was expanded when the U.S. Congress statutorily established such an Office, to be headed by a Deputy Assistant Secretary for Minority Health (Public Law 101-527, the "Disadvantaged Minority Health Improvement Act of 1990," Section 2). Public Law 101-527 also authorized an increase in funding for the Office of Minority Health, to $25 million per year for fiscal years 1991 through 1993. The potential role of the Office in improving the health of minority adolescents is as yet unknown.

U.S. Department of Agriculture

The U.S. Department of Agriculture's Food and Nutrition Services administers a food distribution program for low-income Indians living on or near reservations (206). Participating agencies receive monthly distributions of food from local warehouses. How many Indian adolescents benefit from this program is not known.

U.S. Department of Education

Funding by the U.S. Department of Education of programs focusing on minority adolescent health is limited, but examples of such programs do exist. One is a Drug-Free Schools and Communities Program for Hawaiian Natives to develop a culturally appropriate curriculum for 3,000 Native Hawaiian students. Another is a Drug-Free Schools and Communities Program for alcohol and drug education and prevention among Indian children who live on reservations and attend schools operated or funded by the Bureau of Indian Affairs.

U.S. Department of Justice

The *Office of Juvenile Justice and Delinquency Prevention* (OJJDP) in the U.S. Department of Justice focuses on problems related to delinquency among adolescents in general rather than among any particular group of minority adolescents.[68] Nevertheless, OJJDP does on occasion make efforts to address special issues related to adolescents from minority groups.

For example, OJJDP is funding several research projects on Minorities in the Juvenile Justice System in an effort to determine the extent to which processing decisions are influenced by the racial or ethnic background of the adolescent offender (257).

OJJDP has also provided funding for Proyecto Esperanza. The goal of this project, implemented by the National Coalition of Hispanic Health and Human Services Organizations,[69] is to assess family strengthening and crisis intervention programs and to design model programs to prevent child abuse and reduce the incidence of running away within Hispanic families (110,257). OJJDP has also asked the National Coalition of Hispanic Health and Human Services Organizations to provide technical support to the National Court Appointed Special Advocates Association and the National Council of Juvenile and Family Court Judges to improve the quality of their services to Hispanic children and adolescents at risk of out-of-home placement.

Rural Adolescents: Issues in the Delivery of Health and Related Services

Data from an analysis by McManus indicate that about one-third of all U.S. adolescents ages 10 to 18 live in rural (nonmetropolitan) communities (132). About half of these adolescents live in the South; another one-quarter live in the Midwest (132).

Special Health Issues for Rural Adolescents

Limitations of Data and Research on the Health of Rural Adolescents

It is difficult to determine the health status of rural adolescents for several reasons, only some of them specific to rural areas. First, as discussed throughout this report, there have been few large-scale epidemiologic studies of adolescents. Second, limitations in access to the health care services system for adolescents in general, and for rural adolescents in particular (see below), make clinical samples less than valid as indicators of health status. For example, families of adolescents with complex health problems sometimes may move to metropolitan areas solely because of a lack of specialized services in rural areas. Similarly, when adolescents are treated in metropolitan medical centers, they may not be reflected in clinical prevalence studies as "rural" cases, even though they continue to reside in rural communities. Finally, synthesis of the literature on rural-urban differences is hampered by diverse definitions of rural and by failure to account for confounding variables and the heterogeneity of rural communities.

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[68] See ch. 13, "Delinquency: Prevention and Services," in Vol. II and ch. 19, "The Role of Federal Agencies in Adolescent Health," in this volume for further discussion.

[69] The National Coalition of Hispanic Health and Human Services Organizations is a nonprofit national Hispanic organization focused on improving the health and psychosocial well-being of the Hispanic population (153).

Sufficient data do exist, however, to leave two broad impressions. First, the idyllic image of rural life that may still persist is quite discrepant from reality. Second, although it is a mistake to ignore or underestimate the health risks experienced by rural adolescents, it also seems true that rural adolescents generally are similar to their urban peers in the health problems they experience. Given the extent of health problems among adolescents on average, these impressions are not contradictory. Additional descriptive research designed to separate rural, regional, social class, and ethnic factors and analyses to determine the effects of particular dimensions of rural life on adolescent health would be useful in assessing the true level of health problems among rural adolescents. It would also be useful to have more information on the extent to which rural health facilities meet the needs of rural adolescents.

Health Problems Experienced by Rural Adolescents

As noted earlier, the most comprehensive national health data collected on a continuing basis are National Health Interview Survey data by the National Center for Health Statistics.[70] According to National Health Interview Survey data, the incidence of both acute and chronic conditions in children and adolescents is generally similar in metropolitan and nonmetropolitan areas (132,133). About 75 percent of both metropolitan and nonmetropolitan adolescents report (or, more likely, have reported for them) that their health is excellent or very good (132).

In terms of the prevalence of problems, the most sizable urban-rural differences that show up in available data from a variety of sources reviewed for OTA by Melton and Oberlander are differences in rates of accidental injuries and delinquency (137). Rural adolescents have higher rates of accidental injuries and lower rates of delinquency (137). The prevalence of other problems may not be different for rural and urban adolescents, but the risk factors for the problems may be different.

The American Academy of Pediatrics has identified rural injuries as a major public health problem with unregulated use of farm machinery by adolescents being a prime culprit (10). Using national databases of the National Center for Health Statistics and the Consumer Product Safety Commission, Rivara reported substantial risks for adolescent males in farm families, with farm injuries taking 22.4 per 100,000 lives among 10- to 14-year-old males, 30.9 per 100,000 lives among 15- to 19-year-old males, and accounting for 4,397 emergency room visits among 10- to 19-year-old males in a single year (174). Fatalities resulted most commonly from machinery-related injuries (especially involving tractors), drownings, and firearm accidents (144,174). In addition to severe trauma, farm adolescents are vulnerable to more subtle injuries related to the use of farm machinery, such as noise-induced hearing loss (28). It should also be noted that rural adolescents have been found to engage in behaviors that put them at high risk for automobile and other types of accidents (263).[71]

Data from the National Crime Survey, conducted periodically by the U.S. Department of Justice, shows less victimization by adolescents (and other age groups) in rural than in urban areas.[72] For the most part, however, rural crime and delinquency do not appear to differ in their origins or quality from offending in urban communities (115).

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[70] As discussed above, National Health Interview Survey have several limitations with respect to evaluating the health status of adolescents. One issue is that parents, rather than the adolescents themselves, typically report on their children's health status and health care utilization.

[71] The University of Minnesota survey of 7th through 12th graders in Minnesota found, for example: that only 35 percent of rural adolescents surveyed use their seat belt all or most of the time; that 64 percent of rural adolescent males never used a seat belt; that nearly one out of four rural adolescents surveyed (and three times more males than females) never wear a helmet when riding a motorcycle; that fewer than half the rural adolescents surveyed say they would *not* drink and drive; that only 43 percent said they would not ride with a driver who used alcohol or drugs; that about 20 percent sometimes ride with a driver who's been using alcohol or drugs; that rural adolescents start drinking earlier and drink more often and drink in greater quantity than urban adolescents (263).

Data on mental health problems among rural adolescents are scarce (155). The few epidemiologic studies of adolescents that have included rural-urban comparisons have shown somewhat more risk in urban communities (e.g., 179). However, the surveys and studies tend to vary on so many dimensions (e.g., ethnicity, social class) other than size of community that the research gives little understanding as to any protective factors that may be associated with rural communities per se. There are, however, characteristics of rural life, both longstanding and contemporary, that may affect the mental health and coping ability of rural adolescents differently from adolescents living in metropolitan areas. On the negative side, there is substantial evidence that farm youth have been at greater risk of stress in recent years, in part as a result of the farm crisis of the early 1980s (see 57). Researchers have documented a substantial increase in guilt, alienation, aggressiveness, depression, helplessness, and poor school performance in rural adolescents (18, 70,155,261). One study of 4,300 15- to 19-year-olds in three communities in rural Minnesota, conducted in the early 1980s at the peak of the farm crisis, found that 3 percent reported having attempted suicide in the past month (70). The University of Minnesota Adolescent Health Survey found that about 10 percent of rural females and 7 percent of rural males reported having attempted suicide at one point, and about 3 percent of students had both attempted suicide and were seriously considering taking their own lives at the time of the survey (263). Rural adolescents who live on farms worried about killing themselves at two times the rate of other adolescents (263). Thirty percent of Minnesota respondents had experienced the suicide of a fellow student or adult in the school, and 14 percent had experienced the loss in the previous school year (263).

In addition to change related to the recent farm crisis, perennial instability in many rural communities has resulted from constant migration away from such communities and, during the 1970s, reverse migration, as the dominant rural industries in particular regions have "boomed" and "busted" (29,162). More generally, simply because the range of institutions and social situations is relatively narrow in small communities, change within rural communities is likely to have a greater impact than comparable change in larger communities (271).

Conversely, the relatively low complexity of life and slow diffusion of innovations in rural communities may also contribute to a lack of excitement about the future (137). As evidence, those who stay behind are more likely to be high school dropouts (19.5 v. 16.0 percent[73]), twice as likely to be married during adolescence (3.4 percent among nonmetropolitan adolescents), and less likely to have at least some college education (35.0 v. 44.5 percent[74]) (132).

However, there are many positive aspects to life in rural communities. In general, rural communities are viewed as desirable places to live, in large part because of the greater sense of neighborliness that can arise from "undermanning" (14),[75] and a lower rate of crime than in more densely populated communities (104,271). Many of the pressures experienced by adolescents in rural communities are similar to those experienced by adolescents in urban and suburban communities (e.g., 178).[76]

Access to Health Services by Rural Adolescents

Adolescents in rural areas face special barriers to access to health services, in terms of availability, affordability, and approachability. Perhaps reflecting this differential accessibility and affordability, rural adolescents, especially those who are from poor families, do use health services somewhat less frequently than their urban peers. Nonmetropolitan adolescents have been found to report 2.7 physician visits per year, compared with 3.2 visits annually among metropolitan adolescents (132). On the other hand, the proportion of nonmetropolitan adolescents who report having been hospitalized in the previous year is somewhat higher than among metropolitan adolescents (5.4 percent v. 3.9 percent) (132). It is unclear whether this discrepancy results from differences in accessibility of outpatient care, severity of health needs, or some other factor.

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[72] See ch. 13, "Delinquency: Prevention and Services," in Vol. II for a discussion of delinquency.

[73] These data refer to heads of household.

[74] These data refer to heads of household.

[75] "Undermanning" results when there are more socially necessary roles to be filled than there are people to fill them (14). This phenomenon can have positive health consequences, because it is positively associated with a greater press for personal involvement, and thus more personal control, which in turn have been shown to be related to positive physical and mental status (165). Such general features of rural life as "undermanning" do not always apply to rural adolescents, however. For example, as small rural schools are consolidated into larger institutions, students may become alienated and show behavior problems and psychosomatic disorders (15,69).

[76] In their review for OTA, which was limited by scant information, Melton and Oberlander found no clear urban-rural differences in substance use or in sexual behavior or attitudes (137). There were, however, more studies, and more variations in results, on the topic of substance use. Studies of maltreatment were not able to be analyzed in terms of rural-urban differences.

The availability of professionally staffed mental and physical health services is often limited in rural communities (137,204). Surveys of rural mental health professionals have shown that professionals who choose to work in rural areas tend to be people who received their graduate training in a rural locale. There is a need, then, for more clinical training programs in rural areas. Only 20 percent of physicians, few of them specialists, practice in rural areas; similarly, mental health professionals are concentrated in urban areas. One consequence of the lack of providers is that adolescents in rural areas are especially likely to receive their health care from hospital clinics, and are relatively unlikely to have any consistent source of care. Furthermore, even when services are available, transportation problems may make them inaccessible and, therefore, functionally unavailable to adolescents in rural areas.

Adolescents in rural areas also face economic barriers to care, as Medicaid benefits tend to be more limited in rural States, and many rural families are poor (204). In 1984, 19.3 percent of adolescents in nonmetropolitan areas lived in poverty, compared with 15.5 percent in metropolitan areas (132), but the difference in median family income between metropolitan and nonmetropolitan areas is more striking ($30,045 v. $21,956 in 1985 [158]). In addition, disadvantaged rural families are less likely to be eligible for public assistance programs, as poor parents in rural communities are commonly employed for at least part of the year.

Even when help is available, it may not be sought due to the strong sense of individual responsibility characteristic of many rural people. A study of welfare programs (including AFDC, food stamps, and Medicaid) throughout Wisconsin showed perceptions of stigma to be much greater in rural communities (170).[77] Perhaps as a result, welfare exits in rural communities were substantially more frequent and faster—an outcome that is positive in most respects, but that may signal a willingness to give up needed health services when they are perceived as a sign of personal weakness. In a survey that was conducted among adolescents, the University of Minnesota found that, overall, 25 percent of rural adolescents tried to solve their problems on their own rather than seek help from parents, doctors, friends, clergy, or school people; adolescents living on farms were less likely than other rural adolescents to seek help for problems, even though, as noted above, they were more likely to be troubled (263).[78] However, the survey was not able to determine whether the adolescents who did not seek help were extremely self-reliant, undesirous of help, or unable to go and get help (263).

Although the population of rural America is predominately white, some regions contain substantial numbers of racial and ethnic minorities. For example, the majority of Native Americans live in rural communities, large numbers of blacks live in the rural South, and many Hispanics live in the rural Southwest. Much of the disproportionate poverty of rural America is accounted for by such communities. Consequently, it is important to consider cultural differences when planning and delivering health services to adolescents in rural areas. In addition, it seems important to consider whether rural adolescents live on a farm, because farm youth appear to have different health risks (e.g., serious injury), attitudes toward help seeking, and access to health care, than nonfarm youth.

Major Federal Programs Pertaining to Rural Adolescents

Despite the number of programs that can indirectly affect rural adolescents, it is striking how few Federal programs directly address the health and related needs of rural adolescents (137). Of most relevance to rural adolescents are the Office of Rural Health Policy in the Health Resources and Services

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[77] This study was not adolescent-specific.

[78] As a group, they do not seek contraception information from anyone (25 percent), they are less likely to get health information or care without parental consent (71 percent), and they do not seek out other family members as resources as readily as other young people (22 percent) (263).

Administration (HRSA) of DHHS[79]; the Office of Rural Mental Health Research in the Alcohol, Drug Abuse, and Mental Health Administration of DHHS[80]; and the Extension Service in the U.S. Department of Agriculture, which funds 4-H programs.[81] In addition, the National Center for Nursing Research at the National Institutes of Health is funding a $500,000 grant to identify psychological and environmental health-compromising behaviors in early adolescents in a rural area (79). The community health center program administered by HRSA's Bureau of Health Care Delivery and Assistance provides grants to about 600 public and nonprofit entities to provide primary health care to medically underserved populations, and about 60 percent of the grantees are located in rural areas of the country (241) (see discussion in section on Federal programs for poor adolescents above; also see 137), and a number of recent congressional initiatives dealing with training of rural health professionals and reduction of rural-urban disparities in health care reimbursement policies (204) also have the potential to positively affect the delivery of health services to adolescents in rural areas, albeit indirectly.

As a general matter, the Secretary of DHHS responded to a recommendation of the National Advisory Committee on Rural Health that a national adolescent health demonstration program be established in five rural community sites, by saying that he had decided to make adolescent health an area of emphasis *throughout* DHHS for budget year 1992 (247).

Conclusions and Policy Implications

Certain groups of adolescents—adolescents living in poverty, racial and ethnic minority adolescents, and adolescents living in rural areas—experience health problems at disproportionate rates and face barriers to health care because of lack of financial resources, limited local availability of resources, or other factors.

Poor Adolescents

In 1987, nearly one-third of U.S. adolescents lived in families with incomes that did not exceed 150 percent of the Federal poverty level. One of the primary determinants or whether an adolescent was living in poverty was living arrangement. Adolescents who were living with both parents or with their father were far less likely to be living in poor families than were adolescents living with their mother only or adolescents living on their own.

The effects of growing up poor are complex and not well understood (154). It is well known that children growing up in poverty confront more risk factors and benefit from fewer protective and supportive factors than their more advantaged peers. Among the risk factors that many (though not all) poor children confront are a highly stressed and disorganized family environment, dilapidated housing, substandard schools, and often, especially in inner cities, dangerous, blighted neighborhoods where crime and violence seem to have become the norm (71). Access to health care for poor adolescents appears to be limited, based on utilization data and known barriers to access (e.g., low physician participation in Medicaid, problems with transportation, lack of services in poor areas). The rates of many health and related problems (e.g., days of restricted activity due to acute and chronic conditions, overall self-reported fair or poor health, school dropout, adolescent pregnancy, cigarette smoking, involvement in serious forms of delinquency, victimization) are higher among poor than nonpoor adolescents.

Research on the predictors of resiliency among adolescents from disadvantaged backgrounds (e.g., impoverished homes or dysfunctional families) is receiving increasing attention from researchers, although it has received little Federal support. Past research on this topic suggests that having access to supportive individuals and networks, and the ability to draw upon existing networks (e.g., through greater social competence and intelligence), are important factors in helping adolescents overcome adverse circumstances. For many adolescents these factors may be amenable to intervention.

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[79] HRSA's Office of Rural Health Policy was established in 1987 and as of August 1989 had seven professionals (246). Its role in rural adolescent health has been limited. The Work Group on Health Services of the National Advisory Committee on Rural Health Office has targeted teenage health as a focus because of concern about adolescent suicide, pregnancy, and lack of access for health and mental health services.

[80] The Office of Rural Mental Health Research was established in the National Institute of Mental Health in 1990 to coordinate and administer relevant research and demonstration studies (204). This office will administer a newly advertised research effort that will include grants to rural mental health research centers (233).

[81] The U.S. Department of Agriculture's Extension Service is discussed more fully in ch. 19, "The Role of Federal Agencies in Adolescent Health," in this volume.

Racial and Ethnic Minority Adolescents

Currently, about half of black, Hispanic, and American Indian adolescents, and one-third of Asian-American adolescents, live in poor or near-poor families. The disproportionate occurrence of health problems that is found among adolescents in these racial, ethnic, and tribal groups is attributable at least in part to their low socioeconomic status and the lack of access to health care that is associated with being poor. A long history of discrimination against people of color may contribute to stress in racial and ethnic minorities (e.g., 100,176).

Among the pressing prevention and service needs for racial and ethnic minority adolescents include preventive mental health and mental health outreach programs for Hispanic, Asian, and American Indian and Alaska Native adolescents; dental care and fluoridation for American Indian and Alaska Native, and Hispanic adolescents; dental care for low-income black adolescents; victimization and violence prevention for black adolescents in poor neighborhoods; pregnancy prevention services for black and Hispanic adolescents; HIV prevention and treatment services for black and Hispanic adolescents. In general, however, these problems are not restricted to these groups, and the sources of the problems are not related to race per se (e.g., genetically based), but to complex interactions among economic, neighborhood, and societal factors.

There is an increasing consensus that services for racial and ethnic minority adolescents would be improved if they were "culturally competent." Culturally competent services for adolescents may be difficult to design, though, because there is little systematic information about how racial and ethnic minority and poor adolescents experience adolescence. There is beginning to be some systematic analysis of what a culturally competent system of care is, but the knowledge base has not yet been applied systematically to the design of training programs for health care and other service providers. Overall, there is little systematic description of how services have been developed or adapted to meet the specific needs of racial and minority adolescents, and less scientific evaluation of the effectiveness of available services. There are, however, very few health care providers who are racial or ethnic minorities. The number who are racial and ethnic minorities and trained to work specifically with adolescents is not known.

As health care providers and policymakers consider the impact of racial or ethnic minority status on individual adolescents and the impact of coming into adolescence on individuals from specific racial or ethnic minority groups, they should take numerous factors into account. Such factors include:

- demographic factors (e.g., the size of the adolescents' minority group; its relative distribution in the wider society and the adolescent's immediate community; and its geographic location, whether urban or rural);
- historical factors (e.g., whether the group at large immigrated voluntarily or was forced to relocate to the United States; the history of discrimination against the group); and
- contemporary "sociocultural" factors (e.g., the beliefs, values, social perceptions, and behaviors of the minority group at large; available social institutions, such as the role of a church or religion).

Health care providers and policymakers should also recognize that the adolescent's basic challenge of forming an identity may be made more difficult for those racial and ethnic minority adolescents who are faced with the challenge of straddling two (or more) cultures.

Rural Adolescents

With the exception of the higher rate of accidental injuries (due in part to farm injuries) and lower rate of delinquency for adolescents living in rural areas, there are few known sizable rural-urban *differences* in adolescent health. Although research on adolescents living in rural areas is limited, this suggests that rural adolescents are at least as likely to experience many of the same health problems experienced by adolescents in metropolitan areas. However, additional descriptive research designed to separate rural, regional, social class, and ethnic factors is needed, in addition to analyses to determine the possibly differential effects of particular dimensions of rural life (e.g., living on a farm v. in a town) on adolescent health and well-being.

Rural adolescents' access to health services is limited by shortages of professionally staffed mental and physical health services, transportation problems, and less access to Medicaid in rural States (204). Thus, adolescents in rural areas are especially likely to receive their health care from hospital clinics, and are relatively unlikely to have any consistent source of care (137). Some research suggests that adolescents who live on farms are particularly unlikely to have access to sources of health care (263). Innovations in efforts to provide more comprehensive and integrated services will have to be adapted to the specific needs of rural adolescents, and specific limitations in health care resources (e.g., the relative scarcity of health care professionals).

Summary

As is documented throughout this Report, U.S. adolescents face a number of health problems that could very well be ameliorated by access to health and related services.[82] Thus, the conventional wisdom that adolescents as a group are so healthy they do not require health services is not justified. It is disturbing, then, to note that many adolescents face barriers to access to health services. Some of the barriers are common to individuals in other age groups (e.g., lack of health insurance, inadequate coverage), but some of them are unique to, or particularly affect, adolescents (e.g., lack of independent income, requirements for parental consent, lack of information about the need for and availability of health services). This chapter pulls together evidence that some groups of adolescents—adolescents in poor families, racial and ethnic minority adolescents, and rural adolescents—are particularly at risk for selected health problems and for problems in access. Rather than stereotyping adolescents by one factor or another, however, it is important to note that the health issues and barriers to service faced by any adolescent depend on a variety of interrelated factors. Adolescents who are poor, minority, and living in a rural area will face somewhat different issues than those who are poor, minority and living in an impoverished inner-city area. The families of black adolescents may subscribe to health-related beliefs and behaviors that differ from those of poor white rural adolescents, of recently arrived immigrants from Cambodia, or of Native Hawaiians.

Unfortunately, a lack of research attention to issues affecting many of the adolescents discussed in this chapter typically makes it difficult to design a detailed and specific public policy response to these adolescents' health and related needs. Thus, an enhanced commitment to research on the health needs and developmental experiences of poor, racial and ethnic minority adolescents, and adolescents in rural areas, and the relationships among these specific background factors, should be a top priority for appropriate public policy intervention. Unfortunately, the development of an integrated and comprehensive research base may be impeded by the fragmented Federal approach to adolescent health issues.[83]

As an adequate research base is developed, however, much of the information provided in this chapter and elsewhere in this Report can be used to help improve the health of those adolescents particularly at risk. Examples of changes that could be made at the Federal level and elsewhere include the following:

- Expand support for training of racial and ethnic minority, rural, and low-income health care providers with an interest in adolescent health care;
- Support training in cultural competence for health care providers who work with racial and ethnic minority adolescents, incorporating evaluations of the effects of such changes;
- Support the expansion of data collection efforts to oversample racial and ethnic minority adolescents and to include information on socioeconomic status;
- Collect data on the availability and accessibility of health services for racial and ethnic minorities, rural, and poor adolescents, with such research to include adolescents' perceptions of accessibility and availability;
- Support efforts to improve environments in poor areas (including hard-hit farm-belt communities, Indian reservations, and inner cities), focusing on family support, improving school environments, improving substandard housing, increasing access to nutritional food, increasing access to recreational and fitness facilities and

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[82] For a summary, see Vol. I, "Summary and Policy Options" of this Report.

[83] See ch. 19, "The Federal Role in Adolescent Health," in this volume, and Vol. I, "Summary and Policy Options."

activities, and, where needed, increasing access to appropriate adult role models.[84]

In addition, the major policy options suggested as a result of OTA's analysis are designed to help improve in particular the lives of those adolescents at greatest risk of health problems.[85] Finally, OTA finds that any policy changes should be undertaken with attention to a guiding principle of providing a prolonged sympathetic and supportive environment for all adolescents, of whatever socioeconomic status, race, ethnicity, or residence. Such a change in policy orientation is essential to help adolescents face a crucial turning point in their lives, and may be essential to the well-being of the Nation as well.[86]

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[84] Additional examples of specific options related to the delivery of services to poor adolescents, racial and ethnic minority adolescents, and rural adolescents can be found in Vol. I of this Report, "Summary and Policy Options."

[85] Major options, applicable to the needs of many U.S. adolescents, are summarized in the Introduction to this Volume, and discussed in depth in Vol. I of this Report, "Summary and Policy Options." Options related to specific health problems and other crosscutting issues may also have implications for poor, racial and ethnic minority, and rural adolescents; these are listed in Vol. I of this Report, "Summary and Policy Options."

[86] The need for, and implications of, such a guiding principle are discussed further in Vol. I, "Summary and Policy Options."

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Chapter 19

THE ROLE OF FEDERAL AGENCIES IN ADOLESCENT HEALTH

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Chapter 19

THE ROLE OF FEDERAL AGENCIES IN ADOLESCENT HEALTH

Introduction

The Federal Government has both direct and indirect involvement in providing services, developing policies, designing and implementing programs, and conducting research aimed at improving the health of adolescents. Some Federal efforts target adolescents specifically, and other Federal efforts are aimed at a more general population that includes adolescents. Because of the way funds are allocated, it is difficult to ascertain the extent to which the Federal Government supports activities designed to improve the health of adolescents.

As part of its adolescent health project, OTA surveyed Federal agencies that it identified as possibly having a role in adolescent health. The survey included agencies of the U.S. Department of Health and Human Services (DHHS) and of the U.S. Departments of Agriculture, Commerce, Defense, Education, Interior, Justice, Labor, and Transportation, and several independent Federal agencies such as ACTION (see table 19-1). Agencies were asked about the following:

- their definition of adolescence;
- current agency research priority areas;
- overall agency budgets for fiscal years 1979 through 1990;
- level of funding for adolescent initiatives for fiscal years 1979 through 1990;
- research activities and demonstration projects related to adolescents;
- participation in intra-agency and interagency coordination activities related to adolescents; and
- data collection activities related to adolescents.

The findings of OTA's survey clearly indicate that the Federal Government funds numerous activities aimed at improving the health of adolescents. This chapter analyzes the information sent to OTA in response to its survey questionnaire regarding Federal agencies' adolescent health initiatives. Unless otherwise indicated, the information in this chapter is from Federal agency responses to this questionnaire. Other sources of information are used to provide context to the discussion.

The Federal agencies that were sent OTA's survey questionnaire were also invited to send representatives to OTA for a 1-day discussion on the Federal role in adolescent health. OTA's workshop for Federal agencies was held in October 1989, and the discussions are summarized and incorporated into the conclusions of this chapter.

Federal Agencies' Definitions of the Adolescent Population

The Federal agencies responding to OTA's survey define adolescence inconsistently (see table 19-2). Definitions of adolescence or the ages it encompasses vary not only from one Federal department to another but also within departments and even within agencies.

The variation in definitions of adolescence is particularly evident within the Public Health Service of DHHS. Within the National Institutes of Health, for example, the National Institute of Child Health and Human Development defines adolescence as including, but not being restricted to, ages 12 and 19. Other institutes within the National Institutes of Health define adolescence very broadly. The National Institute of Neurological Disorders and Stroke, for example, defines adolescence as the period between late childhood and early adulthood.

Within the Centers for Disease Control, the definition of adolescence also varies. It is ages 10 to 19 in the Division of Adolescent and School Immunization and ages 10 to 18 in the National AIDS Information and Education Program. Further, within the Health Resources and Services Administration's Bureau of Health Care Delivery and Assistance, definitions of adolescence vary by program:

- community/migrant health centers programs, ages 10 to 19;
- homeless programs, ages 15 to 19;
- perinatal programs, under age 15 and ages 15 to 19; and
- substance abuse programs, ages 13 to 19.

A significant number of Federal agencies and programs do not define any particular age grouping as adolescence. These include the Family Support Administration of DHHS, the Bureau of the Census

Table 19-1—Primary Functions of U.S. Executive Branch Agencies With a Role in Adolescent Health[a]

Agency	Primary function(s)
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS)	Administers a wide range of programs related to health, welfare, and income security.
1. Family Support Administration (FSA)	Administers various programs intended to strengthen the American family.
A. Office of Family Assistance	Administers the Aid to Families With Dependent Children (AFDC) program and the Job Opportunities and Basic Skills Training (JOBS) program.
B. Office of Child Support Enforcement	Supports State efforts to enforce support obligations owed by absent parents to their children.
C. Office of Community Services	Administers the community services block grant and discretionary grant programs, which assist poor people.
2. Health Care Financing Administration (HCFA)	Administers the Medicaid[b] and Medicare programs.
3. Office of Human Development Services (OHDS)	Oversees various human services programs for the elderly, children and youth, families, Native Americans, persons living in rural areas, and people with disabilities.
A. Administration for Native Americans	Advises the Assistant Secretary for Human Development Services on matters related to American Indians and other Native Americans. Administers a grant program and provides technical assistance to Native American organizations to help them implement locally determined social and economic development strategies.
B. Administration on Development Disabilities	Administers the Development Disabilities Act and supports the development and coordination of programs for developmentally disabled persons of all ages.
C. Administration for Children, Youth, and Families	Funds comprehensive services for young children and their families through the Head Start program. Administers provisions of the Child Abuse Prevention and Treatment Act and manages a national clearinghouse on child abuse and neglect. Provides Federal support for child welfare services (including Federal funds for foster care maintenance). Administers the Runaway and Homeless Youth Act and a drug abuse prevention program for runaway and homeless youth.
4. Public Health Service (PHS)	Supports a wide variety of efforts to improve the physical and mental health of Americans.
A. Alcohol, Drug Abuse, and Mental Health Administration	Supports efforts to increase knowledge about and to prevent and treat alcohol and drug abuse and mental health disorders in the United States.
• National Institute on Alcohol Abuse and Alcoholism	Conducts and supports research on alcohol abuse and alcoholism.
• National Institute on Drug Abuse	Conducts and supports research on drug abuse.
• National Institute of Mental Health	Conducts and supports research on mental health and the prevention and treatment of mental illness.
• Office for Substance Abuse Prevention	Supports innovative prevention demonstration projects for individuals at high risk for drug or alcohol abuse; supports an information clearinghouse with drug and alcohol abuse prevention materials; provides technical assistance to States; supports training for substance abuse counselors.
• Office for Treatment Improvement	Supports efforts by States and communities to improve drug and alcohol abuse treatment programs; administers the alcohol, drug abuse, and mental health services block grant program.
B. Centers for Disease Control	Administers national programs for the prevention and control of communicable diseases; chronic diseases; and environmental health problems.
• Center for Chronic Disease Prevention and Health Promotion	Directs a national program aimed at the prevention of premature mortality, morbidity, and disability due to chronic illnesses.
—Division of Adolescent and School Health	Administers programs to reduce health risks to adolescents through comprehensive school health education and other means.
—Division of Reproductive Health	Administers programs and conducts research in areas related to contraception, pregnancy, human reproduction, and infancy.

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[a] The Federal agencies listed in this table are primarily agencies that responded to a survey conducted by OTA in August 1989 to determine the scope and level of adolescent-health-related activity at the Federal level.

[b] Medicaid was established in 1965 under Title XIX of the Social Security Act to assist States in providing health care (e.g., inpatient and outpatient medical services, family planning services, prenatal care) to the poor.

Continued on next page

Table 19-1—Primary Functions of U.S. Executive Branch Agencies With a Role in Adolescent Health[a]—Continued

Agency	Primary function(s)
• Center for Environmental Health and Injury Control	Directs a national program aimed at promoting a healthy environment and preventing premature death, avoidable illness, and disability caused by environmental and related factors.
—Division of Injury Control	Administers and directs programs on the prevention and control of intentional and unintentional injuries.
—Division of Birth Defects and Developmental Disabilities	Administors programs directed toward determining the environmental causes of selected adverse reproductive outcomes and perinatal and childhood disabilities.
• Center for Infectious Diseases	Directs a national program aimed at improving the identification, investigation, diagnosis, prevention, and control of infectious diseases.
—Division of HIV/AIDS	Conducts studies, develops guidelines, evaluates programs and disseminates information on the prevention of human immmunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS).
• Center for Prevention Services	Directs national programs of assistance involving preventive health services to State and local health agencies.
—Division of STDs and HIV Prevention	Administers programs, in cooperation with other CDC components, for the prevention and control of sexually transmitted diseases (STDs), including HIV infection.
• National AIDS Information and Education Program	Disseminates information about HIV infection and AIDS to the public through various means (mass media, national information hotline, and clearinghouse).
• National Center for Health Statistics	Collects, analyzes, and disseminates health statistics on activities that relate to health status, needs, and resources.
C. Health Resources and Services Administration (HRSA)	Oversees a number of programs on general health services and resource issues relating to access, equity, quality, and cost of care; helps coordinate government and private efforts on behalf of rural health facilities.
• Bureau of Health Care Delivery and Assistance	Supports States and communities in their efforts to plan, organize, and deliver health care services to medically underserved populations, and to special services populations such as migrants and homeless people. Administers the National Health Service Corps Program.
• Bureau of Health Professions	Undertakes efforts to improve the education, distribution, and quality of health care professionals in the United States.
• Bureau of Maternal and Child Health[c]	Supports States and communities in their efforts to plan, organize, and deliver health care services to mothers and children. Awards maternal and child health block grants to States and discretionary grants for developing models of health care delivery to mothers and children, including adolescents.
D. Indian Health Service (IHS)	Provides health services for American Indians and Alaska Natives.
E. National Institutes of Health (NIH)	Conducts and supports biomedical research into the causes, prevention, and care of diseases.
• National Cancer Institute	Conducts and supports research on the causes, prevention, diagnosis, and treatment of cancer.
• National Eye Institute	Research on the eye and visual disorders.
• National Heart, Lung, and Blood Institute	Conducts and supports research on the causes, diagnosis, prevention, and treatment of heart, blood vessel, lung, and blood diseases. Conducts educational activities related to the prevention of these diseases.
• National Institute of Allergy and Infectious Diseases	Conducts and supports research on the causes, characteristics, prevention, control and treatment of a wide variety of diseases believed to be attributable to infectious agents, to allergies, or to other deficiencies or disorders in the responses of the body's immune mechanisms.
• National Institute of Arthritis and Musculoskeletal and Skin Diseases	Research on arthritis (including juvenile arthritis) and musculoskeletal and skin disorders (e.g., muscular dystrophies, acne).

[c] In 1990, the Bureau of Maternal and Child Health and Resources Development split into two separate bureaus: 1) the Bureau of Maternal and Child Health, and 2) the Health Resources Development Bureau.

Table 19-1—Primary Functions of U.S. Executive Branch Agencies With a Role in Adolescent Health[a]—Continued

Agency	Primary function(s)
• National Institute of Child Health and Human Development	Conducts and supports multidisciplinary behavioral and biomedical research on child health and maternal health, on problems of human development (e.g., mental retardation) and on family structure. Supports research on new contraceptives and AIDS.
• National Institute of Dental Research	Research aimed at eliminating tooth decay and an array of other oral-facial disorders.
• National Institute of Diabetes and Digestive and Kidney Diseases	Conducts and supports research into the causes, prevention, diagnosis, and treatment of various metabolic and digestive diseases (e.g., juvenile diabetes, cystic fibrosis, sickle-cell anemia, hemophilia).
• National Institute of Environmental Health Sciences	Conducts and supports research to understand the effects of chemical, biological, and physical factors in the environment on health.
• National Institute of Neurological and Communicative Disorders and Stroke (NINCDS)[d]	Conducts and supports research on neurological disorders (e.g., head and spinal cord injury) and stroke.
• National Center for Nursing Research	Administers programs and research training programs aimed at promoting the quality of research in nursing and patient care, including care for adolescents.
F. Office of the Assistant Secretary of Health (OASH)	Aids the Secretary of Health with management responsibilities of the department.
• Office of Disease Prevention and Health Promotion	Supports and coordinates prevention programs within the Alcohol, Drug Abuse, and Mental Health Administration, the Centers for Disease Control, the Food and Drug Administration, the Health Resources and Services Administration, and the National Institutes of Health.
• Office of Minority Health	Ensures that DHHS funds are used to address minority health problems by organizing, and assessing current programs for minority health problems; provides technical assistance to States and local governments with respect to their efforts to address minority health issues.[e]
• Office of Population Affairs	Carries out Public Health Service Act Title X and Title XX programs related to adolescent pregnancy, family planning, and population research.
G. Social Security Administration	Administers the Old Age Survivors and Disability Insurance Program and the Supplemental Security Income Program.
ACTION	Administers several Federal domestic volunteer service programs, including VISTA, the Foster Grandparents Program, and Student Community Service Projects.[f]
NATIONAL SCIENCE FOUNDATION	Supports research in science and engineering through grants to universities and other research organizations.
U.S. CONSUMER PRODUCT SAFETY COMMISSION	Collects information on consumer-product related injuries, promotes research on the causes and prevention of such injuries, develops voluntary or mandatory standards for consumer products, and sometimes bans hazardous products.
U.S. DEPARTMENT OF AGRICULTURE (USDA)	Administers a wide range of programs related to farms, nutrition, food, hunger, rural development, and the environment.
1. Office of the Assistant Secretary, Food and Consumer Services	
A. Food and Nutrition Service	Administers several programs to make food assistance available to needy people, including the Food Stamp Program, the School Breakfast Program, the Food Distribution Program, and the Special Supplemental Food Program for Women, Infants, and Children. Also gives grants to States for disseminating nutrition information to children.
B. Human Nutrition Information Service	Performs research in human nutrition; monitors food and nutrient consumption in the United States; and disseminates information on nutrition.

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[d] In 1990, the National Institute of Neurological and Communicative Disorders and Stroke split into two separate institutes: 1) the National Institute of Neurological Disorders and Stroke, and 2) the National Institute on Deafness and Other Communication Disorders.

[e] These were its functions prior to the passage of Public Law 101-527, which established separate funding for an Office of Minority Health in DHHS.

[f] These were its functions prior to passage of the National and Community Service Act (Public Law 101-610).

Table 19-1—Primary Functions of U.S. Executive Branch Agencies With a Role in Adolescent Health[a]—Continued

Agency	Primary function(s)
2. Office of the Assistant Secretary, Science and Education	
A. Extension Service	Serves as USDA's educational agency and is the Federal partner in the Cooperative Extension System, a nationwide educational network that provides access to food- and agriculture-related research, science and technology. Recent initiatives include programs on human nutrition, youth at risk, building human capital, and family and economic well-being.
U.S. DEPARTMENT OF COMMERCE	Administers a wide range of programs to promote the Nation's international trade, economic growth, and technical advancement.
1. Bureau of the Census	Collects, tabulates, and publishes or otherwise makes available a wide variety of statistical data on the U.S. population and the economy.
U.S. DEPARTMENT OF DEFENSE	Oversees U.S. military forces and various civilian defense agencies.
1. Office of Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)	Administers a civilian health and medical program for retirees and spouses and dependents of active duty, retired, and deceased members of the military.
U.S. DEPARTMENT OF EDUCATION	Establishes policy for, administers, and coordinates most Federal assistance for education.
1. Office of the Assistant Secretary for Elementary and Secondary Education	Formulates policies for, directs, and coordinates programs for elementary and secondary education. Administers grants to States and local school districts for Indian and migrant education, as well as grants to help schools meet the educational needs of educationally disadvantaged children (e.g., neglected or delinquent children under State care).
2. Office of the Assistant Secretary for Educational Research and Improvement	Administers functions concerning research, statistics, demonstrations, and assessment. Administers discretionary grants to improve health education for elementary and secondary students.
3. Office of the Assistant Secretary for Special Education and Rehabilitative Service	Administers programs in special education and provides services designed to meet the needs and develop the full potential of handicapped children.
4. Office of Bilingual Education and Minority Languages Affairs	Provides support for programs to meet the special educational needs of minority languages populations.
5. Office of the Assistant Secretary for Vocational and Adult Education	Administers programs of grants and assistance for vocational and technical education and coordinates rural education programs.
U.S. DEPARTMENT OF THE INTERIOR	Has responsibility for the stewardship of nationally owned lands and natural resources; has trust responsibilities for American Indian reservations.
1. Bureau of Indian Affairs	Works with American Indian and Alaska Native people to develop and implement educational, social, and community development programs.
U.S. DEPARTMENT OF JUSTICE	Has broad responsibilities related to law enforcement, including oversight of the Federal Bureau of Investigation, the Drug Enforcement Administration, the Bureau of Prisons, the U.S. Marshals Service, the Immigration and Naturalization Service, and the Department's Civil Rights Division, Antitrust Division, Tax Division, Civil Division, Criminal Division, Environment and Natural Resources Division, etc.
1. Office of Justice Programs[g]	
A. Bureau of Justice Assistance	Provides financial and technical assistance to States and local governments to control drug abuse and violent crime and improve the criminal justice system.

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[g] The Office of Justice Programs was established by the Justice Assistance Act of 1984 and reauthorized in 1988 to help foster cooperation and coordination needed to make the criminal justice system function effectively.

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Table 19-1—Primary Functions of U.S. Executive Branch Agencies With a Role in Adolescent Health[a]—Continued

Agency	Primary function(s)
B. Bureau of Justice Statistics	Collects, analyzes, and disseminates information about crime, and the operation of the criminal justice system at all levels of government.
C. National Institute of Justice	Works to improve the criminal justice system, address crime prevention and control, and enhance community safety and security.
D. Office of Juvenile Justice and Delinquency Prevention	Administers programs and policies intended to improve the juvenile justice system; assists communities in responding to the needs of juveniles; assesses the factors that contribute to juvenile delinquency; and informs practitioners about research findings and successful interventions.
E. Office for Victims of Crime	Carries out activities mandated by the Victims of Crime Act of 1984.
U.S. DEPARTMENT OF LABOR	Fosters U.S. workers' welfare, improves their working conditions, and promotes opportunities for employment.
1. Employment and Training Administration	Has responsibilities related to employment services, unemployment insurance, and job training. Administers the Job Training Partnership Act, which authorizes block grants to States for job training programs for economically disadvantaged individuals and provides authority for the Job Corps.
U.S. DEPARTMENT OF TRANSPORTATION	Develops coordinated national transportation policies and oversees a wide variety of transportation programs carried out by nine operating administrations (aviation, highway, railroad; highway traffic safety; urban mass transportation, etc.).
1. Federal Highway Administration	Administers the Federal-aid highway program of financial assistance to the States for highway construction and improvements, such as highway repairs and maintenance, which improve the safety of the roads; exercises jurisdiction over commercial motor carriers in interstate commerce.
2. National Highway Traffic Safety Administration	Carries out programs and research related to the safety and performance of motor vehicles, and related equipment.
NATIONAL TRANSPORTATION SAFETY BOARD	Conducts independent investigations of accidents and other safety problems, conducts studies, and makes recommendations to Federal agencies, the transportation industry, and others on safety measures and policies.

SOURCE: U.S. Congress, Office of Technology Assessment, 1991, based on National Archives and Records Administration, Office of the Federal Register, *The United States Government Manual 1990/91* (Washington DC: U.S. Government Printing Office, July 1, 1990).

Table 19-2—How Adolescence Is Defined by Different Federal Agencies and Their Components

Federal agency	Definition of adolescence	Distinctions between early, middle, and late adolescence	Reason(s) for definition or distinctions chosen
ACTION	10 to 19	None	Executive policy decision
U.S. CONSUMER PRODUCT SAFETY COMMISSION	None. Often, age groups are related to factors, such as product design or physical characteristics, of the population. Data are usually reported as ages 5 to 14 and 15 to 24.	None	Not applicable
U.S. DEPARTMENT OF AGRICULTURE			
Office of the Assistant Secretary, Science and Education • Extension Service's 4-H Program	Age guideline of 9 to 19. Most States have adopted an earlier age for participation.	Early: < 11. Middle: 11 to 14. Late: 15 to 19.	Lower age limit of 9 chosen because of the need to work with younger adolescents due to health-related issues.
Office of Assistant Secretary, Food and Consumer Services • Food and Nutrition Service	None. Some data are collected by single year of age or school grade. For example, the Food Stamp Program reports on children and adolescents ages 5 to 17 receiving food stamps.	None	Not applicable
U.S. DEPARTMENT OF COMMERCE Bureau of the Census	Not specified. Data are reported by single year of age and for various age groups (i.e., 10 to 14 and 15 to 19); data user can pay for other age breaks.	None. Data users can create their own age groups.	Requests from data users and the judgments of the Census Bureau's professional staff.
U.S. DEPARTMENT OF DEFENSE	Two military services use 10 to 18. Remaining two use 12 to 18.	Yes[a]	Programs are geared to adolescents based on their growth, development, and maturation levels.
Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)	None. Individuals less than age 21 are considered children, and those over 21 are considered adults. Data are collected for 10- to 14-year-olds and 15- to 19-year-olds.	None	Statutes determine age when it is a factor for eligibility.
U.S. DEPARTMENT OF EDUCATION	Although no Department-wide definition exists and definitions may vary by program, adolescents are generally considered to be in grades 7 through 12.	None	Traditional grouping
Office of Elementary and Secondary Education	None	None	Not applicable
• Office of Indian Education	None	None	Not applicable
• Office of Migrant Education	Unofficially, 10 to 21.	None	Not applicable
Office of Special Education and Rehabilitative Services	None		

[a] Definitions not provided.

Continued on next page

Table 19-2—How Adolescence Is Defined by Different Federal Agencies and Their Components—Continued

Federal agency	Definition of adolescence	Distinctions between early, middle, and late adolescence	Reason(s) for definition or distinctions chosen
• Office of Special Education Programs	None. Ages 12 to 17 and 18 to 21 are used in the *Annual Report to Congress.*	No specific distinctions. However, States report child data as 6 to 11, 12 to 17, and 18 to 21.	Legislatively mandated[b]
• National Institute on Disability and Rehabilitation Research	None. Age groupings may or may not be defined within project guidelines.	Not unless done within a specific project.	Legislatively mandated[b]
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES			
Assistant Secretary for Planning and Evaluation	10 to 18	Yes[a]	Age 10 generally marks the beginning of puberty, and at age 18 individuals are no longer eligible for ASPE social services.
Family Support Administration	Not specified. For recipient children under age 18, data are reported by year, and parent recipients are reported by age group 11 to 18.	Not provided	Not provided
Health Care Financing Administration	None. Eligibility for Medicaid includes individuals less than age 18.	None	Not applicable
Office of Human Development Services	Varies. Social services block grants: varies. Child welfare services: under 21. Child welfare research: not specified. Foster care: under 18. Independent living program: over 16. Runaway & homeless youth program: 10 to 18.	Sometimes made in discretionary priorities.	Required under legislative authority: Adoption Assistance Act (Public Law 92-272)—under age 18 except where mental or physical handicap warrants continuation until age 21. Child Abuse Prevention and Treatment Act (Public Law 93-247)—under age 18 or as specified by the State's child protection law.
Public Health Service			
A. Alcohol, Drug Abuse, and Mental Health Administration			
• National Institute on Alcohol Abuse and Alcoholism	13 to 21	None	Not applicable
• National Institute on Drug Abuse	None. Research projects target the range of 12- to 21-year-olds.	None. Studies test programs for adolescents of differing ages.	Determined by study questions and research subject eligibility.
• National Institute of Mental Health	No NIMH-wide definition, but the Child and Adolescent Disorders Research Branch defines adolescence as 10 to 18.	Does not code grants by these categories, but NIMH clinical investigators often use such categories— Early: 10 to 13. Middle: 14 to 17. Late: 18 to 24.	Age groups make sense developmentally in terms of psychosocial stressors and role transitions.

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[a] Definitions not provided.

[b] Services may be provided until age 22 under the Education for All Handicapped Children Act (Public Law 94-142). Title I of the Rehabilitation Act provides for delivery of service to individuals with potential vocational abilities with no set lower age limit. The Fair Labor Standards Act, however, established the age of 14 as appropriate for employment. Most school districts target the age of 16 as eligible for employment.

Table 19-2—How Adolescence Is Defined by Different Federal Agencies and Their Components—Continued

Federal agency	Definition of adolescence	Distinctions between early, middle, and late adolescence	Reason(s) for definition or distinctions chosen
• Office for Substance Abuse Prevention	Under age 21. Data age breaks include adolescent ages 10 to 12, 13 to 15, 16 to 18, 19 to 21.	Early: 10 to 14. Middle: 14 to 17. Late: 17 to 20.	Based on convenience of program administration, as with school-based programs, and on findings in developmental psychology literature. Under 21 age group defined by OSAP's authorizing legislation.
B. Centers for Disease Control			
• Center for Chronic Disease Prevention and Health Promotion			
—Division of Adolescent and School Health	10 to 19	Yes[c]	Uses the World Health Organization definition.
—Division of Reproductive Health	12 to 19	Early: 12 to 14. Middle: 15 to 17. Late: 18 to 19.	Very few births occur to adolescents under age 12. Fifteen to 17-year-olds may still be in school and the proportion married is different than the 18- to 19-year-olds.
• Center for Environmental Health and Injury Control	None	None	Not applicable
—Division of Injury Control	None	None	Not applicable
—Disabilities Prevention Program	None	None	Not applicable
• Center for Infectious Diseases			
—Division of HIV/AIDS	13 to 19	None	Children under age 12 unlikely to become infected with the AIDS virus through sexual contact. Age 19 is still considered an adolescent.
• Center for Prevention Services			
—Division of Immunization	10 to 24	Early: 10 to 14. Middle: 15 to 19. Late: 20 to 24.	Standard age groups of the Census Bureau.
—Division of STDs and HIV Prevention	10 to 19. Data provided for adolescents ages 10 to 14 and 15 to 19.	None	For STD morbidity purposes, there are differences in infection rates between 10- to 14-year-olds and 15- to 19-year-olds.
—Division of Tuberculosis Control	10 to 19. Data provided for adolescents ages 10 to 14 and 15 to 19.	None	Age groups used by other CDC surveillance programs.
—National AIDS Information and Education Program	10 to 18	None	Selected on the advice of the Division of Adolescent and School Health and the advice of national youth-serving organizations.
• National Center for Health Statistics	No uniform definition. NCHS does collect data on all age groups, by individual year.	None	Not applicable

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[c] Although the Division of Adolescent and School Health does not have a standard definition for early, middle, and late adolescence, the Division does distinguish between age groups in particular cases. For example, the "Guidelines for Effective School Health Education To Prevent the Spread of AIDS" includes information appropriate for early elementary, late elementary/middle school, and junior/senior high school students (18).

Continued on next page

Table 19-2—How Adolescence Is Defined by Different Federal Agencies and Their Components—Continued

Federal agency	Definition of adolescence	Distinctions between early, middle, and late adolescence	Reason(s) for definition or distinctions chosen
C. Health Resources and Services Administration			
• Office of Rural Health Policy	None. Does not collect data on adolescents.	None	Not applicable
• Bureau of Health Care Delivery and Assistance	Varies by program: Community/Migrant Health Center (C/MHC): 10 to 19. Homeless: 15 to 19. Perinatal: < 15 and 15 to 19. Substance abuse: 13 to 19.	None	C/MHC age grouping is based on those used by the Census Bureau. Others are program specific.
• Bureau of Maternal and Child Health and Resources Development[d]			
—Office of Maternal and Child Health	10 to 19	Distinguished only within program activities.	Based on Title V (Maternal and Child Health Services Block Grant) legislation and the recommendation of adolescent health professionals.
D. Indian Health Service	None. However, IHS health care providers accept the 10 to 19 definition. Data can be sorted by any age grouping.	None	Not applicable
E. National Institutes of Health			
• National Cancer Institute	12 to 19	Not provided	Not provided
• National Center for Nursing Research	13 to 18	Not provided	Not provided
• National Center for Research Resources	Puberty to maturity[e]	Not provided	Not provided
• National Eye Institute	Not provided	Not provided	Not provided
• National Heart, Lung, and Blood Institute	Generally, ages 12 to 18 for school-based programs. Ages 10 to 12 are considered preadolescents.	Not provided	Not provided
• National Institute of Allergy and Infectious Diseases	13 to 20	Not provided	Not provided
• National Institute of Arthritis and Musculoskeletal and Skin Diseases	12 to 21	Not provided	Not provided
• National Institute of Child Health and Human Development	Includes, but is not restricted to, ages 12 to 19.	Not provided	Not provided
• National Institute of Diabetes and Digestive and Kidney Diseases	12 to 21	Not provided	Not provided
• National Institute of Neurological and Communicative Disorders and Stroke[e]	Period between late childhood and early adulthood. Most hospitals and other clinical centers conducting research supported by the Institute consider those under 16 as children and those older than 16 as young adults.	Not provided	Not provided

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[d] Following OTA's survey, the Bureau of Maternal and Child Health and Resources Development split into the Bureau of Maternal and Child Health and the Bureau of Health Resources Development (see fig. 19-1). Responses were received from the original Bureau.

[e] In 1990, the National Institute of Neurological and Communicative Disorders and Stroke split into two separate institutes: 1) the National Institute of Neurological Disorders and Stroke, and 2) the National Institute on Deafness and Other Communication Disorders.

Table 19-2—How Adolescence Is Defined by Different Federal Agencies and Their Components—Continued

Federal agency	Definition of adolescence	Distinctions between early, middle, and late adolescence	Reason(s) for definition or distinctions chosen
F. Office of the Assistant Secretary for Health			
• Office of Disease Prevention and Health Promotion	None	None	Not applicable
• Office of Population Affairs	None, but frequently targets 10- to 19-year-olds.	None, but recognizes that adolescents of different ages have varying degrees of need.	Uses data compiled by other agencies, such as the Census Bureau.
U.S. DEPARTMENT OF THE INTERIOR	Not provided	Not provided	Not provided
U.S. DEPARTMENT OF JUSTICE			
National Institute of Justice	None, but specific research projects may address issues relevant to particular groupings.	None	Not applicable
Office of Juvenile Justice and Delinquency Prevention	None[1]	None	Not applicable
U.S. DEPARTMENT OF LABOR			
Job Training Partnership Act Programs	Primarily ages 16 to 21. Limited programs for 14- to 15-year-olds.	Services for 14- and 15-year-olds are different than for 16- to 21-year-olds.	Legislatively mandated
Bureau of Apprenticeship and Training	Age 16 and over. Data can be obtained for different age groups, but is not routinely summarized in a report.	None	Not applicable
U.S. DEPARTMENT OF TRANSPORTATION			
Federal Highway Administration	Ages 10 to 20. Data stored by age so different age groupings possible.	Early: 10 to 14. Middle: 15 to 17. Late: 18 to 20.	Primarily because of driving/drinking cutoffs. The 15- to 17-year-olds are the learner/limited experienced drivers; the 18- to 20-year-olds are the more experienced drivers and before 1987 were often legal drinkers.
National Highway Traffic Safety Administration	None. Targets the 15- to 24-year-old group, especially those under 21. Age groups most frequently used in data collection, < 15, 15 to 17, 18 to 20.	None	Ages 15 to 24 represent the most traffic fatalities, injuries, and years of life lost in almost every motor vehicle crash category.
NATIONAL TRANSPORTATION SAFETY BOARD	None	None	Not applicable

[1] Under Title II of the 1974 Juvenile Justice and Delinquency Prevention Act, as amended, the office relies on State laws to define the age of a juvenile for purpose of juvenile or family court jurisdiction over delinquent conduct and noncriminal misbehavior (status offenses).

SOURCE: Office of Technology Assessment, 1991, based on Federal agency responses to the Office of Technology Assessment's 1989 questionnaire regarding adolescent health initiatives.

in the U.S. Department of Commerce, the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) in the U.S. Department of Defense, the U.S. Department of Education, and programs within the U.S. Departments of Justice and Agriculture. Some Federal agencies that do not provide a specific adolescent definition do collect data on various age groups, allowing outside researchers the opportunity to use their own adolescent age groups; these include the Bureau of the Census, the National Center for Health Statistics in DHHS, and the National Highway Traffic Safety Administration in the U.S. Department of Transportation.

Very few Federal agencies distinguish between early, middle, and late adolescence. Among those agencies that do have definitions, there appears to be greater agreement on the definition of early adolescence than on the definitions of middle and late adolescence (i.e., when one ends and the other begins). Federal agencies, including the Division of Immunization within the Centers for Disease Control of DHHS and the Office for Substance Abuse Prevention within the Alcohol, Drug Abuse, and Mental Health Administration of DHHS generally agree that early adolescence spans the ages of 10 to 14. For the Division of Immunization, late adolescence begins at age 20; for the Office for Substance Abuse Prevention, middle adolescence ends at age 17.

The reasons underlying Federal agencies' choice of definitions of adolescence (or lack thereof) are diverse. In some instances, State and Federal law require that adolescents of particular ages receive services. Thus, for example, the Bureau of Maternal and Child Health within the Health Resources and Services Administration of DHHS bases its definition of 10 to 19 years on Title V of the Social Security Act, which authorizes the maternal and child health block grant program.[1] Other Federal agencies, such as the Division of HIV/AIDS and the Division of Reproductive Health within the Centers for Disease Control, base their definitions of adolescence on their own practical experiences. The Federal Highway Administration of the U.S. Department of Transportation defines middle adolescence as ages 15 to 17 and late adolescence as ages 18 to 20, primarily because of the two age groups' differing driving experiences (i.e., 15- to 17-year-olds are considered inexperienced drivers).

The use of differing definitions of adolescence by Federal agencies is understandable and is not necessarily indicative of a problem. As discussed in Volume I, adolescence can be defined in physical, psychological, or social terms. In any event, chronological age is not necessarily consistent with any particular adolescent stage. Differing definitions of adolescence may be troublesome, however, if Federal agencies should be coordinating their efforts, or if some categories of adolescents (e.g., early adolescents, such as 10- and 11-year-olds) who should be receiving attention from a particular agency are excluded from their mission by definition.

Federal Programs and Expenditures for Adolescents

Given the various definitions of adolescence used by Federal agencies, and the way in which Federal funds are spent and distributed at the national, State, and local levels, determining the exact amount of money the Federal Government spends on adolescents is impossible. Some Federal agencies serve adolescents as part of a larger population group receiving Federal funds, so their expenditures on adolescents are unknown. The U.S. Consumer Product Safety Commission and the U.S. Department of Agriculture's Food and Nutrition Service, for example, serve adolescents but do not have specific funds set aside for them. In order to give States greater control in planning, programming, and spending for programs, some Federal funds are distributed to States through block grants. Federal block grant funding is provided for maternal and child health services, social services, education, and alcohol, drug abuse, and mental health services. The provision of funding through block grant programs limits the Federal Government's ability to analyze expenditures on services or programs targeted to specific populations, such as adolescents.

Sometimes, Federal agency priorities are set by the U.S. Congress. Recently, for example, congressional funding decisions have led DHHS to increase its emphasis on activities related to the consequences of adolescent sexual intercourse and illicit drug use. Activities related to the prevention and control of other more prevalent conditions among adolescents, such as injuries, have received relatively little emphasis.

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[1] *Block grants* are sums of Federal funds allotted to State agencies (e.g., education, health) which may be passed onto local agencies. States determine the mix of services provided and the population served and are accountable to the Federal Government only to the extent that funds are spent in accordance with program requirements. Sometimes, however, set-asides are required for specific population groups.

Federal programs and expenditures targeting adolescents within DHHS and other selected Federal agencies are discussed at greater length below. A summary of estimated expenditures by the agencies with the largest roles in adolescent health (broadly defined) can be found in figure 19-1.

U.S. Department of Health and Human Services: Programs and Expenditures for Adolescents

Many DHHS agencies assist or have the potential to assist adolescents through a wide range of social services, health services, and welfare programs, as well as through research and demonstration projects (see figure 19-2). In terms of expenditures for adolescents, however, the Office of Human Development Services and four agencies in the Public Health Service—the Alcohol, Drug Abuse, and Mental Health Administration, the Centers for Disease Control, the Health Resources and Services Administration, and the National Institutes of Health —provide the bulk of adolescent services and programs (see table 19-3).[2] Additional agencies within DHHS, some of which are discussed below, support activities that target or include adolescents.

Family Support Administration

The Family Support Administration of DHHS is responsible for programs intended to strengthen the American family. The Family Support Administration has six major programs, but the primary program affecting adolescents is Aid to Families With Dependent Children (AFDC).[3]

The AFDC program, established in 1935, is a cash assistance program serving needy families with children and is funded jointly by Federal and State governments. States administer the program within broad Federal guidelines, and the Federal Government provides quality control and compliance reviews. The fiscal year 1989 AFDC budget totaled $17.245 billion (103).

To help families meet financial needs and become self-sufficient, all States were required to implement a Job Opportunity and Basic Skills (JOBS) training program by October 1, 1990, under the Family Support Act of 1988. The program gives families receiving AFDC payments the opportunity to take part in education, job training, and work experience programs. As they do with AFDC, States have flexibility to determine the types of services they offer (59).

Under the Family Support Administration's discretionary community service grants program, the Office of Community Services provides an annual grant to the National Collegiate Athletic Association for the National Youth Sports Program, which is a summer recreational program for adolescents from low-income families (32).[4] Hygiene and nutritional information is presented as part of the program. In fiscal year 1990, over $27 million was expected to be awarded for new discretionary community service grants (55 FR 10297).[5] Additionally, community food and nutrition programs include adolescents as part of their service group. Adolescents may also be included as recipients under the emergency community services of the homeless grant program, which distributes funds to 57 States and territories (60). Under this program, States award all funds to community agencies to meet the health needs (e.g., followup and long-term assistance and social services) of homeless individuals, including adolescents.

Health Care Financing Administration

One of the functions of the Health Care Financing Administration of DHHS is to administer the Medicaid program. Medicaid was established in 1965 under Title XIX of the Social Security Act to assist States in providing health care (e.g., inpatient and outpatient medical services, family planning services, prenatal care) to the poor (80,81).

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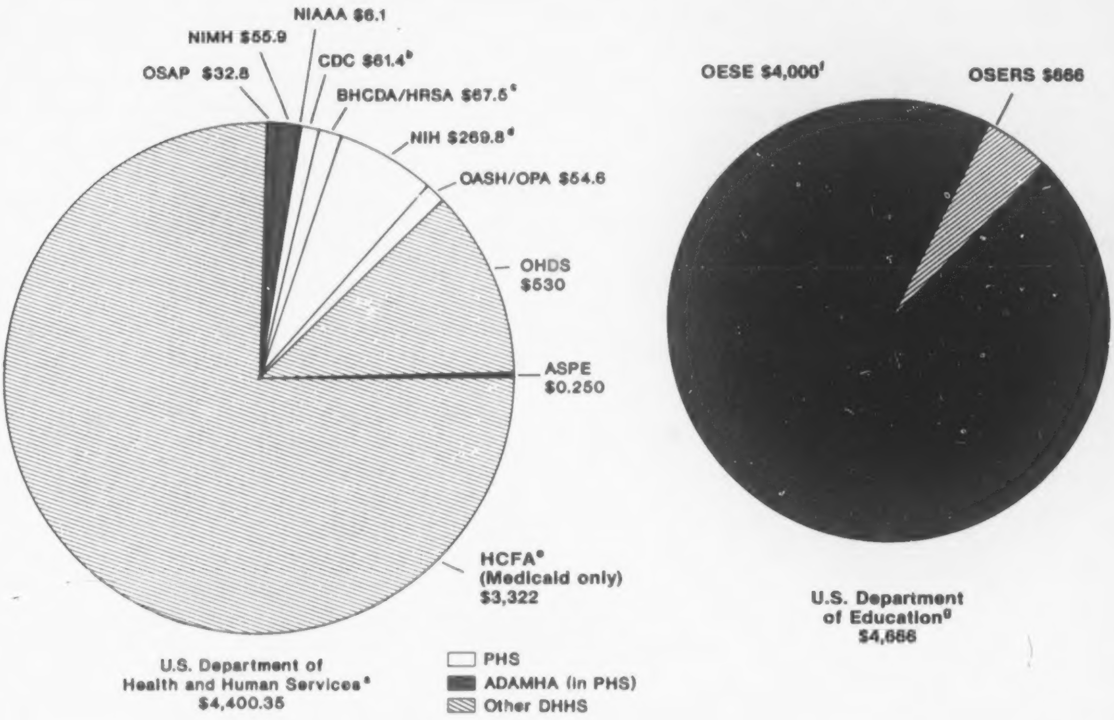
[2] Within these agencies are specific programs having adolescents as a primary focus. These include the Division of Adolescent and School Health within the Centers for Disease Control, the Bureau of Maternal and Child Health within the Health Resources and Services Administration, and the National Institute of Child Health and Human Development within the National Institutes of Health.

[3] The other five programs are Job Opportunity and Basic Skills (JOBS) Training, child support enforcement, refugee and entrant assistance, community services block grant, and low-income home energy assistance (59).

[4] Another grant program is the community services block grant program where grants are provided to States, territories, Indian tribes, and tribal organizations primarily for employment, education, housing, health, and the poor.

[5] This amount does not represent the amount being given to support continuation grants of past projects (103).

Figure 19-1—Estimated Adolescent-Specific Expenditures by U.S. Executive Branch Agencies Responding to OTA's 1989 Survey (dollars are in millions)



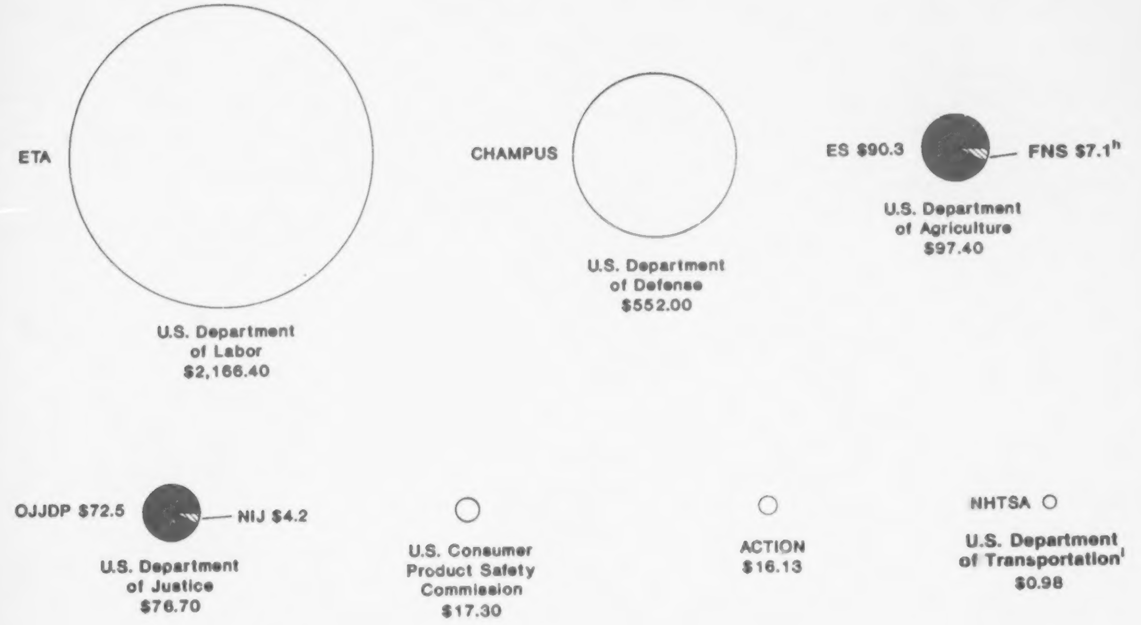
NOTE: Graphs are not drawn to scale. Differences in size are designed to provide rough estimates of differences in adolescent-specific expenditures only.

Key to abbrevations:

ADAMHA—Alcohol, Drug Abuse, and Mental Health Administration
ASPE—Assistant Secretary for Planning and Evaluation
BHCDA—Bureau of Health Care Delivery and Assistance
BMCH—Bureau of Maternal and Child Health
CCDPHP—Center for Chronic Disease Prevention and Health Promotion
CDC—Centers for Disease Control
CEHIC—Center for Environmental Health and Injury Control
CHAMPUS—Civilian Health and Medical Program of the Uniformed Services
CID—Center for Infectious Diseases
CPS—Center for Prevention Services
DI—Division of Immunization
DTC—Division of Tuberculosis Control
ES—Extension Service
ETA—Employment and Training Administration
FNS—Food and Nutrition Service
FSA—Family Support Administration
HCFA—Health Care Financing Administration
HRSA—Health Resources and Services Administration
IHS—Indian Health Service
NAIEP—National AIDS Information and Education Program
NIAAA—National Institute on Alcohol Abuse and Alcoholism
NIDA—National Institute on Drug Abuse
NIH—National Institutes of Health
NIJ—National Institute of Justice
NIMH—National Institute of Mental Health
NHTSA—National Highway Traffic and Safety Administration
OASH—Office of the Assistant Secretary for Health
ODPHP—Office of Disease Prevention and Health Promotion
OESE—Office of Elementary and Secondary Education
OHDS—Office of Human Development Services
OJJDP—Office of Juvenile Justice and Delinquency Prevention
OMH—Office of Minority Health
OPA—Office of Population Affairs
ORHP—Office of Rural Health Policy
OSAP—Office of Substance Abuse Prevention
OSERS—Office of Special Education and Rehabilitative Services
OSH—Office of Smoking and Health
OTI—Office of Treatment Improvement
PHS—Public Health Service
SSA—Social Security Administration

[a] The following agencies within DHHS were unable to provide OTA with the amount spent on adolescents alone: Family Support Administration, Social Security Administration, Indian Health Service, National Institute on Drug Abuse (ADAMHA, PHS), Office of Treatment Improvement (ADAMHA, PHS), National AIDS Information Education Program (CDC, PHS), Office of Safety and Health (CCDPHP, CDC, PHS), Division of Immunization (CPS, CDC, PHS), Division of Tuberculosis Control (CPS, CDC, PHS), Office of Rural Health Policy (HRSA, PHS), Bureau of Maternal and Child Health (HRSA, PHS), Bureau of Health Resources Development (HRSA, PHS), Office of Disease Prevention and Health Promotion (OASH, PHS), Office of Minority Health (OASH, PHS).

[b] This figure includes $33.3 million spent by the Division of Adolescent and School Health (CCDPHP), $0.45 million spent by the Division of Reproductive Health (CCDPHP), $23.7 million spent by the Division of STD/HIV Prevention (CPS), $0.525 million spent by the Division of HIV/AIDS (CID), $3.3 million spent by Division of Injury Control (CEHIC), and $0.158 spent by the Division of Prevention Programs (CEHIC).



[c] This figure includes expenditures by the Bureau of Health Care Delivery and Assistance only. Expenditures on adolescents by other subagencies (e.g., the Bureau of Maternal and Child Health) within HRSA were not provided to OTA.

[d] This figure includes: $19.5 million spent by the National Cancer Institute, $0.148 million spent by the National Center for Nursing Research, $2.1 million spent by the National Center for Research Resources, $15.4 million spent by the National Heart, Lung, and Blood Institute, $98.2 million spent by the National Institute of Allergy and Infectious Diseases, $0.784 million spent by the National Institute of Arthritis and Musculoskeletal and Skin Diseases, $25.1 million spent by the National Institute of Child Health and Human Development, $26.6 million spent by the National Institute of Diabetes and Digestive and Kidney Diseases, $1.3 million spent by the National Institute of Neurological Disorders and Stroke. All are estimates.

[e] Note that the figure of $3,322 million includes both Federal and State contributions to Medicaid spending for adolescents. At OTA's request, HCFA estimated the amount of Medicaid spending for adolescents in fiscal year 1988 (see app. C in this volume). However, HCFA did not calculate the Federal and State shares separately. As discussed in ch. 16 in this volume, many factors could affect estimates of the State share.

[f] This is a very rough estimate by OTA. The Office of Elementary and Secondary Education dispenses most of the funds that are spent by the U.S. Department of Education. The Office has no specific line items for adolescents, because it distributes grants to schools and other organizations for various programs that are not aimed at a particular age group. In 1989, the Office of Elementary and Secondary Education disbursed $6.6 billion for all activities. OTA's estimate is based on the assumption that 10- to 18-year-olds are attending grades 5 through 12, which constitute 66.6 percent of elementary and secondary grades, not including kindergarten. Two-thirds of $6.6 billion is $4.4 billion. Since the percentage of adolescents attending school is likely to be lower than the percentage of younger children attending school, this estimate may be too high. OTA estimates, therefore, that the Office of Elementary and Secondary Education spends about $4 billion on education of adolescents. However, this estimate does not take into account that the cost of adolescents' education may be higher than that of younger students (e.g. more highly trained teachers, more sophisticated lab equipment).

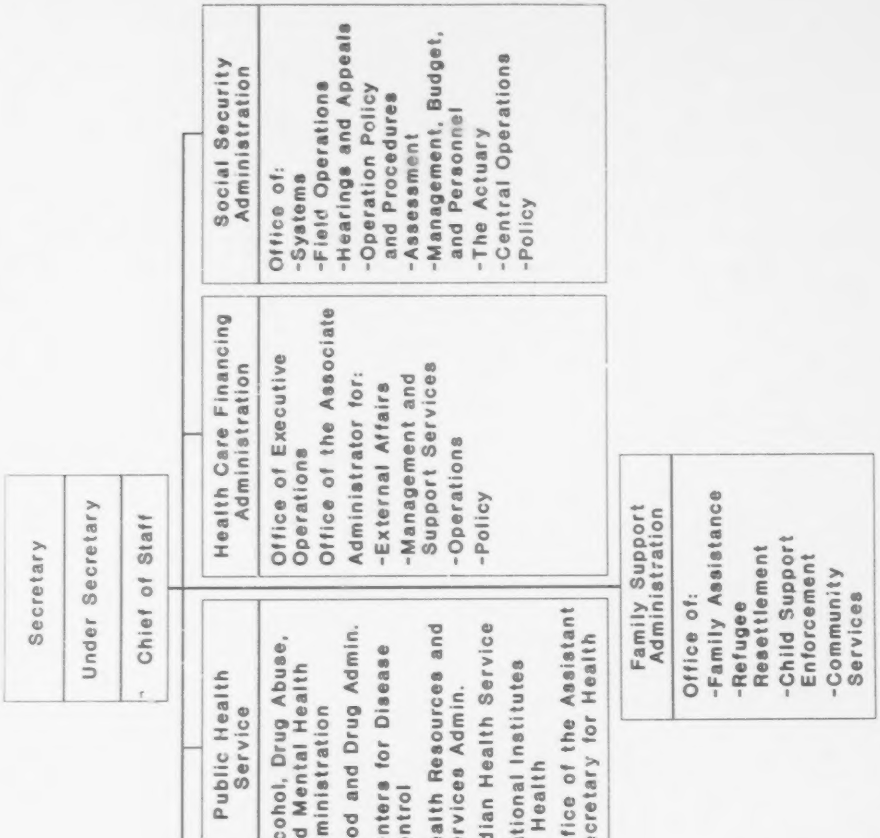
[g] This figure does not include spending by the following offices within the U.S. Department of Education that also serve adolescents: Office of Bilingual Education and Minority Languages Affairs, Office of Planning, Budget, and Evaluation, Office of Postsecondary Education, Office of Vocational and Adult Education. These offices were not able to provide OTA with estimates of spending on adolescents.

[h] This is a very rough estimate by OTA. The figure was tabulated by using the following percentages on how many adolescents were served in the respective programs: 43 percent of the participants in the National School Lunch Program are in grades 7 through 12; 24 percent of those in the School Breakfast Program are in grades 7 through 12; 23 percent of those in the Summer Food Service Program are ages 13 to 18; 3 percent of those participating in the Supplemental Food Program for Women, Infants, and Children are pregnant, breastfeeding, or postpartum females under age 18; and 34 percent of participants in the Food Stamp Program are between the ages of 15 and 17.

[i] This figure does not include the Federal Highway Administration, which also serves adolescents.

SOURCE: Office of Technology Assessment, 1991, based on various responses to the Office of Technology Assessment's 1989 questionnaire regarding adolescent health initiatives, Washington, DC, 1989.

Figure 19-2—U.S. Department of Health and Human Services[a]


Secretary
Under Secretary
Chief of Staff
Office of Human Development Services
Administration:
-on Aging
-for Children, Youth, and Families
-for Native Americans
-on Developmental Disabilities
Office of Program Coordination and Review
Public Health Service
Alcohol, Drug Abuse, and Mental Health Administration
Food and Drug Admin.
Centers for Disease Control
Health Resources and Services Admin.
Indian Health Service
National Institutes of Health
Office of the Assistant Secretary for Health
Health Care Financing Administration
Office of Executive Operations
Office of the Associate Administrator for:
-External Affairs
-Management and Support Services
-Operations
-Policy
Social Security Administration
Office of:
-Systems
-Field Operations
-Hearings and Appeals
-Operation Policy and Procedures
-Assessment
-Management, Budget, and Personnel
-The Actuary
-Central Operations
-Policy
Family Support Administration
Office of:
-Family Assistance
-Refugee Resettlement
-Child Support Enforcement
-Community Services

[a] See text concerning April 1991 proposed reorganization.

SOURCE: Based on U.S. Department of Health and Human Services, organizational chart, Washington, DC, 1990.

In fiscal year 1988, Federal and State spending on Medicaid benefits was $48.4 billion, which includes expenditures for adolescents.[6] Adolescents ages 10 to 18 are eligible for Medicaid coverage if they meet the requirements for AFDC, if they are deemed "medically needy" by their State, or if they meet other conditions outlined by their particular State. Therefore, which adolescents are eligible for Medicaid coverage varies a great deal from State to State. In fiscal year 1988, 4.58 million adolescents between ages 10 and 18 made up 17.1 percent of all Medicaid recipients; expenditures for adolescents in fiscal year 1988 represented 6.9 percent or $3.32 billion of Federal and State Medicaid expenditures (83).

Office of Human Development Services

The Office of Human Development Services of DHHS is the primary social service agency with programs for adolescents (see figure 19-3). In addition to administering Social Security Act Title XX social services block grants to the States,[7] the Office of Human Development Services supports activities that affect adolescents through its Administration on Children, Youth, and Families. This Administration provides Federal support for child welfare services and supports runaway and homeless youth centers.[8] In 1989, the amendments to the Drug Abuse Education and Prevention Act (Public Law 101-93) established and funded two new grant programs under the Office of Human Development Services for education and prevention efforts that target runaway and homeless youth and members of youth gangs.

The Office of Human Development Services' Administration for Native Americans has supported projects related to drug and alcohol abuse prevention among Native Americans. The Office of Human Development Services' Administration on Developmental Disabilities supports the development and coordination of programs for developmentally disabled persons, including adolescents. Recently, the Office of Human Development Services has used a portion of its discretionary money to support initiatives intended to help adolescents avoid alcohol and drug use, complete high school, and postpone pregnancy. In fiscal year 1989, the Office of Human Development Services spent approximately 7.7 percent ($530 million) of its total budget of $6.82 billion on adolescents.

Public Health Service

As noted earlier, four agencies within the Public Health Service of DHHS provide many of the services and programs for adolescents: the Alcohol, Drug Abuse, and Mental Health Administration, the Centers for Disease Control, the Health Resources and Services Administration, and the National Institutes of Health.

Alcohol, Drug Abuse, and Mental Health Administration—Within the Alcohol, Drug Abuse, and Mental Health Administration, five agencies fund diverse activities concerning adolescents (see figure 19-4):

- the National Institute on Alcohol Abuse and Alcoholism,
- the National Institute on Drug Abuse,
- the Office for Substance Abuse Prevention,
- the National Institute of Mental Health, and
- the Office of Treatment Improvement.

Although the priority areas of the agencies within the Alcohol, Drug Abuse, and Mental Health Administration address large societal problems (e.g., alcohol and drug abuse and mental health disorders), the prevention and treatment of these problems among adolescents is seen by the agencies as an important goal.[9]

The National Institute on Alcohol Abuse and Alcoholism, for example, has three priority areas specific to adolescents: defining sociocultural factors that promote adolescents' drinking, developing and testing preventive interventions, and assessing the impact of changes in the drinking age on alcohol consumption (39,65). In fiscal year 1989, the National Institute on Alcohol Abuse and Alcoholism

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[6] For further discussion of Medicaid, see ch. 16, "Financial Access to Health Services," in this volume.

[7] Services supported by social services block grants to States include protective and emergency services, employment, education, and training services for disabled adolescents, foster care and adoption services, and health related services (e.g., prevention, intervention, information, referral, and residential care and treatment). Although service recipients may be of any age group, adolescents receive a significant amount of these services (34).

[8] For further discussion of these centers, see ch. 14, "Homelessness: Prevention and Services," in Vol. II.

[9] For a discussion of alcohol and drug abuse and mental health problems among adolescents, see ch. 12, "Alcohol, Tobacco and Drug Abuse: Prevention and Services," and ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II.

Table 19-3—Components of the Expenditures on Adolescent Health by the U.S. Department of Health and Human Services

DHHS agency with actual or potential role in adolescent health	Total expenditures (most current fiscal year)	Estimated expenditures for adolescents (most current fiscal year)	Percent of expenditures for adolescents
ASSISTANT SECRETARY FOR PLANNING AND EVALUATION	$12,000,000 (1989)[a]	$250,000 (1989)	2 percent
FAMILY SUPPORT ADMINISTRATION	Not provided	Not provided	Not provided
HEALTH CARE FINANCING ADMINISTRATION	$118,200,000,000 (1988)	$3,322,000,000[b]	Not provided[b]
OFFICE OF HUMAN DEVELOPMENT SERVICES	$6,817,162,000 (1989)[c]	$530,000,000 (1989)	7.7 percent
PUBLIC HEALTH SERVICE	Not provided	Not provided	Not provided
Alcohol, Drug Abuse, and Mental Health Administration	$2,700,000,000 (1990)	Not provided	Not provided
• National Institute on Alcohol Abuse and Alcoholism	$125,200,000 (1989)	$6,138,353 (1989)	4.9 percent
• National Institute on Drug Abuse	$379,000,000 (1990)	Not provided	Not provided
• National Institute of Mental Health	$454,604,000 (1989)	$55,947,000 (1989)	12 percent
• Office for Substance Abuse Prevention	$193,000,000 (1990)	$32,800,000 (1990)	17 percent[c]
• Office for Treatment Improvement	$1,268,700,000 (1990)[d]	Not provided	Not provided
Centers for Disease Control	$978,781,000 (1989)	$61,416,000 (1989)[e]	6.2 percent
• Center for Chronic Disease Prevention and Health Promotion	Not provided	Not provided	Not provided
—Division of Adolescent and School Health	$33,300,000 (1989)	$33,300,000 (1989)	100 percent
—Division of Reproductive Health	Not provided	$450,000 (1989)	10 percent[f]
—Office on Smoking and Health	Not provided	Not provided	Not provided
• Center for Environmental Health and Injury Control	Not provided	Not provided	Not provided
—Division of Injury Control	$21,800,000 (1989)[c]	$3,270,000 (1989)[c g]	15 percent[c]
—Disabilities Prevention Program	Not provided	$158,000 (1989)	Not provided
• Center for Infectious Diseases	Not provided	Not provided	Not provided
—Division of HIV/AIDS	Not provided	$525,000 (1989)	Not provided
• Center for Prevention Services	Not provided	Not provided	Not provided
—Division of Sexually Transmitted Diseases and HIV Prevention	Not provided	$23,713,200 (1989)	Not provided
—Division of Immunization	Not provided	Not provided	Not provided
—Division of Tuberculosis Control	Not provided	Not provided	Not provided
• National AIDS Information and Education Program[g]	Not provided	Not specified[h]	Not available

[a] An additional $2 million is allocated every 2 years to the Institute for Research on Poverty (38). The money is appropriated from Congress to the Institute through the Assistant Secretary for Planning and Evaluation.

[b] Figure shown is the proportion of Medicaid funding directed to adolescents only, as calculated for the Office of Technology Assessment by the Health Care Financing Administration. The figure includes both State and Federal Medicaid spending. For further discussion of Medicaid, see ch. 16, "Financial Access to Health Services," in this volume.

[c] Estimated amount.

[d] Eighty-nine percent ($1.133 billion) of these funds are distributed to States as block grants.

[e] Adolescent expenditure total includes only those Centers for Disease Control agencies providing this information in response to the Office of Technology Assessment's survey. Several surveyed agencies did not provide adolescent-specific data, and the National AIDS Information and Education Program could not calculate an amount directed at adolescents.

[f] Ten percent of the Division's staff time is being devoted to evaluation or analysis of adolescent data.

[g] No budget line item specific to adolescents.

[h] "Not specified" indicates that adolescents are included as part of a larger target group. Thus, expenditures cannot be separated out for that particular group.

spent over $6 million (under 5 percent) of its overall budget on activities aimed at adolescents. Current activities focus on adolescent risk-taking and alcohol abuse, the effects of parental and family influences, peer pressure, decisionmaking skills, and personality variables on high school and college students' drinking habits as well as preventive intervention efforts and the impact of parenting-skills training (65,68). Other efforts address the causes, consequences, and treatment of alcohol use (68).[10]

The National Institute on Drug Abuse studied the causes, consequences, and treatment of adolescent drug abuse throughout the 1980s and funded over

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[10] The National Institute on Alcohol Abuse and Alcoholism recently announced its interest in funding an Adolescent Alcohol Research Center which would integrate identification of interactions between adolescent development and alcohol use and testing behavioral and other technologies to prevent alcohol problems. Any non-Federal public or private nonprofit organization could request up to $1.5 million to be awarded annually for 5 years (66). The starting date of the Center would be Dec. 1, 1990. Additionally, in 1988, the National Institute on Alcohol Abuse and Alcoholism announced its interest in studying norm-setting related to alcohol use by parents and families, physicians and their staff, youth peer groups, schools, and community organizations, but did not allocate specific funds to this activity (64).

Table 19-3—Components of the Expenditures on Adolescent Health by the U.S. Department of Health and Human Services—Continued

DHHS agency with actual or potential role in adolescent health	Total expenditures (most current fiscal year)	Estimated expenditures for adolescents (most current fiscal year)	Percent of expenditures for adolescents
Health Resources and Services Administration	Not provided	Not provided	Not provided
• Office of Rural Health Policy	$1,400,000 (1988)	Not available	Not provided
• Bureau of Health Care Delivery and Assistance[i]	$397,058,800 (1989)[c]	$67,500,000 (1989)[j]	17 percent
• Bureau of Maternal and Child Health and Resources Development[k]	Not provided	Not provided	Not provided
Office of Maternal and Child Health[k]	$573,848,000 (1989)[l]	Not available	Not provided
Indian Health Service[m]	$1,020,106,000 (1989)	Not specified[h]	Not available
National Institutes of Health[n]	$7,144,764,000 (1989)	Not provided	Not provided
• National Cancer Institute	$1,468,435,000 (1988)	$19,490,000 (1988)	1.3 percent
• National Center for Nursing Research	$23,361,000 (1988)	$148,000 (1988)	0.6 percent
• National Center for Research Resources	$344,150,000 (1988)	$2,054,000 (1988)	0.6 percent
• National Heart, Lung, and Blood Institute	$965,283,000 (1988)	$15,464,000 (1988)	1.6 percent
• National Institute of Allergy and Infectious Diseases	$638,521,000 (1988)	$98,150,000 (1988)	15 percent
• National Institute of Arthritis and Musculoskeletal and Skin Diseases	$147,543,000 (1988)	$754,000 (1988)	0.5 percent
• National Institute of Child Health and Human Development[o]	$377,167,000 (1988)	$25,093,000 (1988)	6.6 percent
• National Institute of Diabetes and Digestive and Kidney Diseases	$534,400,000 (1988)	$26,600,000 (1988)	5 percent
• National Institute of Neurological and Communicative Disorders and Stroke[p]	$458,792,000 (1988)	$1,327,000 (1988)	0.3 percent
Office of the Assistant Secretary for Health			
• Office of Disease Prevention and Health Promotion	$4,900,000 (1989)	Not provided	Not provided
• Office of Minority Health	$8,000,000 (1990)	Not provided	Not provided
• Office of Population Affairs[q]	$139,928,205 (1989)	$54,572,000 (1989)	39 percent
SOCIAL SECURITY ADMINISTRATION	Not provided	Not provided	Not provided

[i] These data were obtained from R. Abrams, Bureau of Health Care Delivery and Assistance (1).

[j] Although specific funding is not available for adolescent initiatives, the adolescent-specific amount is based on the average number of adolescent medical visits in community/migrant health center programs during 1988.

[k] Following OTA's survey in 1989, the Bureau of Maternal and Child Health and Resources Development split into the Bureau of Maternal and Child Health, formerly the Office of Maternal and Child Health, and the Bureau of Health Resources Development (see fig. 19-1). Responses were received from the original Bureau.

[l] Approximately 80 percent of these funds are distributed to States as block grants.

[m] These data were obtained from G. Brenneman, Indian Health Service (11) and J.M. Lyle, Indian Health Service (23).

[n] The NIH total includes all NIH agencies, not just those able to estimate expenditures on adolescent health initiatives. The 1989 estimate for expenditures is from the Budget of the U.S. Government (102a).

[o] These data were obtained from D. Levenson, National Institute of Child Health and Human Development (21).

[p] In 1990, the National Institute of Neurological and Communicative Disorders and Stroke split into two separate institutes: 1) the National Institute of Neurological Disorders and Stroke, and 2) the National Institute on Deafness and Other Communication Disorders.

[q] These data were obtained from R. Scholle, Office of Population Affairs (37).

SOURCE: Office of Technology Assessment, 1991, based on Federal agency responses to the Office of Technology Assessment's 1989 questionnaire regarding adolescent health initiatives.

160 projects for 7- to 17-year-olds (68,70,73-75).[11] In fiscal year 1990, appropriations for the National Institute on Drug Abuse were $379 million (71). Information on the proportion being spent on adolescents was not available. Recently, the National Institute on Drug Abuse, in conjunction with the U.S. Department of Education, released a program announcement encouraging organizations to study innovative and theory-based drug abuse prevention programs in the schools or to evaluate currently ongoing school-based programs. Additionally, the National Institute on Drug Abuse is interested in granting money to a minority drug abuse prevention research center targeting high-risk children, adolescents, and young adults (74). Organizations can request support for up to 5 years. First-year awards were to be for $600,000, and $750,000 for each subsequent year.

Under the authority of the Anti-Drug Abuse Acts of 1986 and 1988 (Public Laws 99-570 and 100-

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[11] The National Institute on Drug Abuse's overall priorities, mandated by Congress, for fiscal year 1991 are acquired immunodeficiency syndrome (AIDS) prevention, improving drug abuse treatment and prevention, and studying maternal drug abuse and its effect on children.

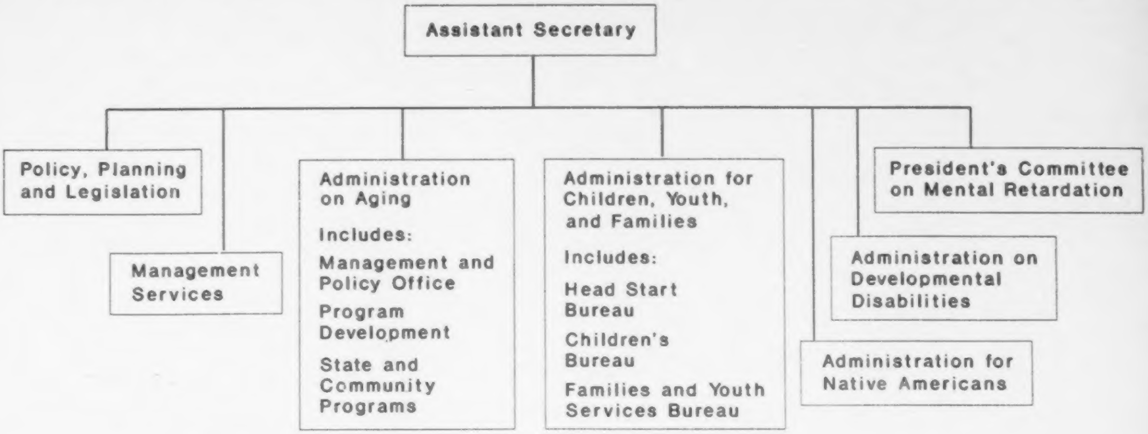
Assistant Secretary
Policy, Planning and Legislation
Management Services
Administration on Aging
Includes:
Management and Policy Office
Program Development
State and Community Programs
Administration for Children, Youth, and Families
Includes:
Head Start Bureau
Children's Bureau
Families and Youth Services Bureau
President's Committee on Mental Retardation
Administration on Developmental Disabilities
Administration for Native Americans

Figure 19-3—U.S. Department of Health and Human Services, Office of Human Development Services[a]

[a] See text concerning April 1991 proposed reorganization.

SOURCE: *Federal Organization Service: Civil* (Washington DC: Carroll Publishing Co., February/March 1990).

690), the Office for Substance Abuse Prevention's general priority areas for the May 1989 review cycle (this includes fiscal year 1989 and the beginning of fiscal year 1990) were high-risk youth, pregnant and postpartum women and children, community youth activities, and a community partnership prevention program.[12] Office for Substance Abuse Prevention grants are designed to identify promising strategies for working with youth who are at high risk for alcohol and other drug use.[13] Forty-five percent ($5.6 million) of the high-risk youth grants focus on adolescents ages 12 to 20, and approximately 39 percent ($5.9 million) of the community youth activities grants focus on adolescents who are at risk of dropping out of school or being involved with gangs. The Office for Substance Abuse Prevention's budget increased substantially from about $69 million in fiscal year 1989 to $193 million in fiscal year 1990 (79).

The National Institute of Mental Health has several programs with an interest in adolescents. Two of the immediate goals of the National Institute of Mental Health's Division of Clinical Research are to address all of the major mental disorders of adolescents, such as affective and anxiety disorders, youth suicide, learning disorders, and mental illness/mental retardation, and to increase studies on the effectiveness of treatment, particularly in the area of adolescent depression. The Division also wants to expand the availability of manpower in the area of research on adolescent disorders by expanding research training and research career development support.[14] The National Institute of Mental Health's Child and Adolescent Service System Program (CASSP) under the Division of Applied and Services Research (formerly the Division of Education and Service Systems Liaison) tries to improve systems for service delivery to severely emotionally disturbed adolescents under age 18 by changing the way communities and States deliver services (e.g., improving the availability of continuums of care and involving parents and families) (76,78).[15] In 1989,

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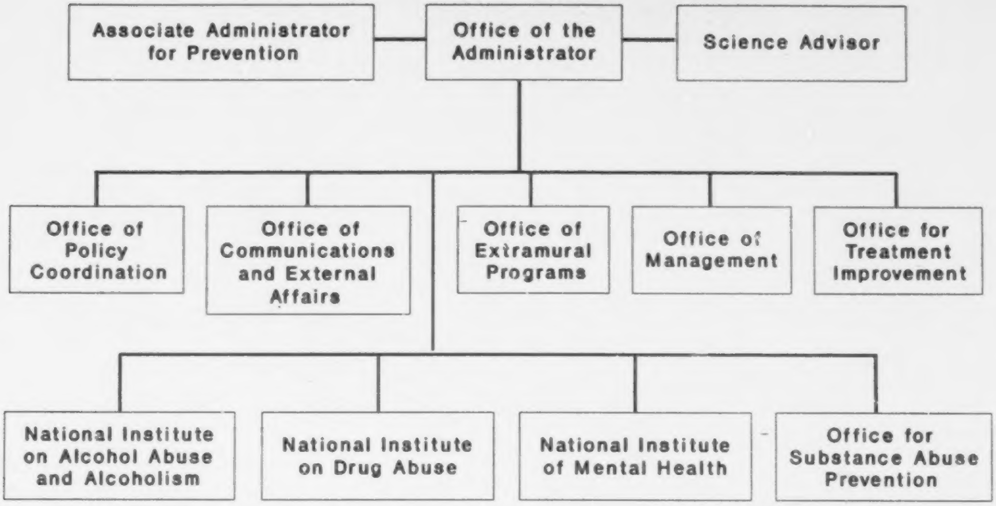
[12] The Office for Substance Abuse Prevention funds only demonstration projects. Individuals interested in research projects are encouraged to apply to other agencies.

[13] One Office for Substance Abuse Prevention program, the Community Partnership program, attempts to bring together all the knowledge gained from grant programs focused on individual target groups and apply this knowledge systematically to entire communities using public/private partnerships. Approximately $50 million was proposed in fiscal year 1990 for grants to 150 to 200 communities.

[14] The Antisocial and Violent Behavior Branch of the Division of Biometry and Applied Sciences has as a research priority the prevention of antisocial and highly aggressive behavior in childhood and adolescence. The Division of Education and Service Systems Liaison priorities included State-level service system development and service delivery to all children and adolescents.

[15] Demonstration projects under CASSP are funded under four types of grants: capacity building, State- and community-level system development, and strategy evaluation grants (77). In fiscal year 1989, $200,000 was available for 4 State capacity building projects, $2 million for 12 new State- and community-level projects, $300,000 for 10 State-level strategy evaluation grants, $1.3 million for 8 renewal projects, and $900,000 for 31 strategy evaluation supplements. No guarantee was available for funding beyond the first year (77).

Figure 19-4—U.S. Department of Health and Human Services, Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration


Associate Administrator for Prevention
Office of the Administrator
Science Advisor
Office of Policy Coordination
Office of Communications and External Affairs
Office of Extramural Programs
Office of Management
Office for Treatment Improvement
National Institute on Alcohol Abuse and Alcoholism
National Institute on Drug Abuse
National Institute of Mental Health
Office for Substance Abuse Prevention

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration, Rockville, MD, organizational chart, 1990.

CASSP projects were in 42 States and 11 localities for a total of $9.8 million, of which $1 million was targeted to services research for the homeless (78).

Finally, the new Office for Treatment Improvement within the Alcohol, Drug Abuse, and Mental Health Administration is responsible for improving the quality of treatment services for individuals suffering from drug abuse and other problems, such as alcoholism and physical and mental illness (72). The Office for Treatment Improvement administers alcohol, drug abuse, and mental health services block grants to States for application in the areas of mental health and substance abuse. In fiscal year 1990, Congress appropriated $1.133 billion for such block grants, $237.5 million for use in mental health and $895.6 million for use in substance abuse (17). Fiscal year 1990 appropriations for the Office for Treatment Improvement, apart from block grant funding, were $135.7 million. The Office is funding a grant demonstration program which targets three critical populations: adolescents, racial and ethnic minorities, and residents of public housing projects. The projects in this program are Model Comprehensive Treatment Programs for Critical Populations ($25 million in funding in 1990), Cooperative Agreements for Drug Abuse Treatment Improvement Projects in Target Cities ($28 million in funding in 1990), and Model Drug Abuse Treatment Programs for Non-Incarcerated Criminal Justice Populations ($8 million in funding in 1990) (6).

Centers for Disease Control—Within the Centers for Disease Control, numerous programs, particularly the Division of Adolescent and School Health within the Center for Chronic Disease Prevention and Health Promotion, respond to various health needs of adolescents (see figure 19-5).[16] The Centers for Disease Control agencies responding to OTA's survey[17] indicated that for fiscal year 1989, approximately $61 million was targeted specifically for

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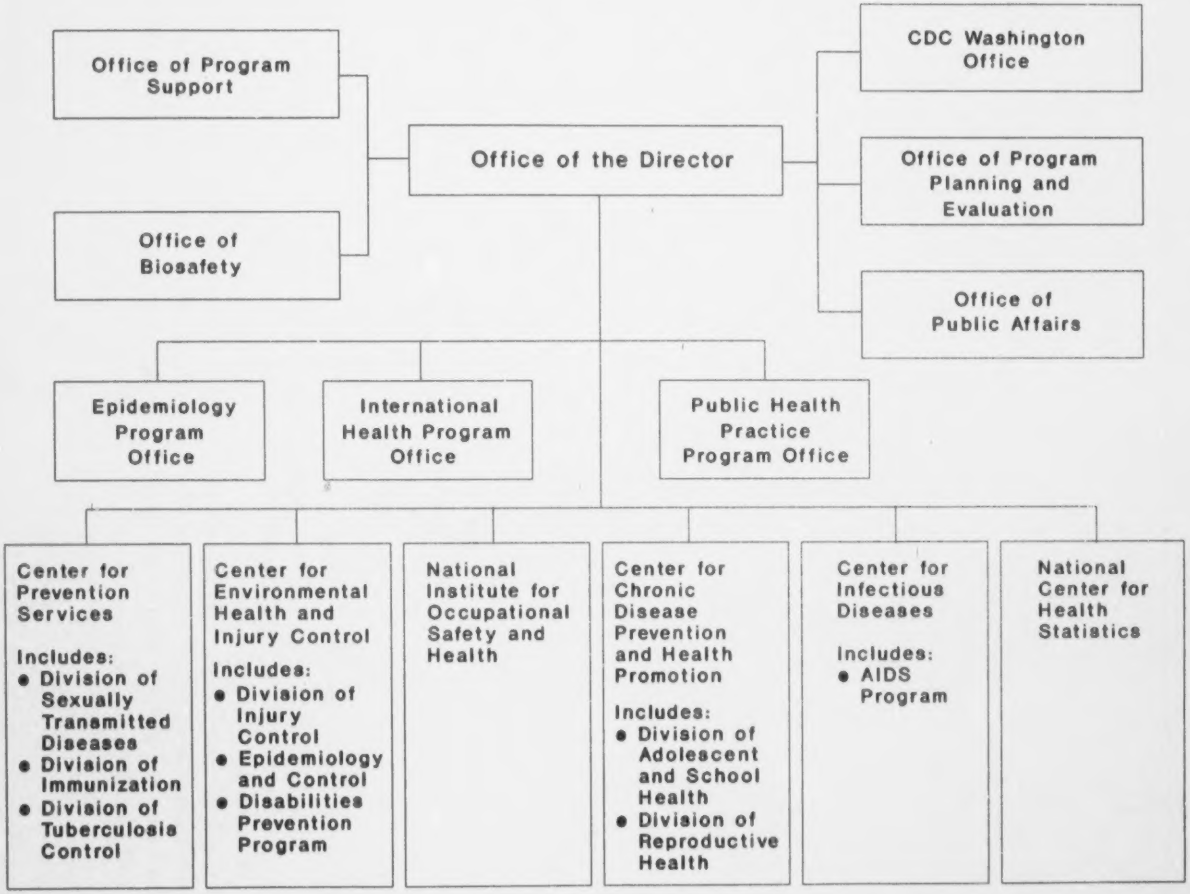
[16] Originally, the Division of Adolescent and School Health was the Office of School Health and Special Projects whose mission was to develop a national school health program for the prevention of human immunodeficiency virus (HIV)/AIDS. In October 1988, the Center for Chronic Disease Prevention and Health Promotion was created, and the Office of School Health and Special Projects was elevated to become the Division of Adolescent and School Health.

[17] Centers for Disease Control agencies that responded to OTA's questionnaire included the Center for Chronic Disease Prevention and Health Promotion, Center for Environmental Health and Injury Control, Center for Infectious Diseases, Center for Prevention Services, and the Deputy Director, HIV.

Figure 19-5—U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control


Office of Program Support
Office of Biosafety
Office of the Director
CDC Washington Office
Office of Program Planning and Evaluation
Office of Public Affairs
Epidemiology Program Office
International Health Program Office
Public Health Practice Program Office
Center for Prevention Services
Includes:
• Division of Sexually Transmitted Diseases
• Division of Immunization
• Division of Tuberculosis Control
Center for Environmental Health and Injury Control
Includes:
• Division of Injury Control
• Epidemiology and Control
• Disabilities Prevention Program
National Institute for Occupational Safety and Health
Center for Chronic Disease Prevention and Health Promotion
Includes:
• Division of Adolescent and School Health
• Division of Reproductive Health
Center for Infectious Diseases
Includes:
• AIDS Program
National Center for Health Statistics

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, organizational chart, Atlanta, GA, Aug. 1, 1990.

adolescents, representing about 6 percent of the Centers for Disease Control's total budget.[18]

Major adolescent-health related programs administered by the Centers for Disease Control include the following:

- the Youth Risk Behavior Surveillance System that provides national, State, and local data about the incidence and prevalence of risk behaviors (e.g., behaviors resulting in unintentional injuries, human immunodeficiency virus (HIV) infection and other sexually transmitted diseases (STDs), alcohol and drug use, tobacco use, improper diet, and insufficient physical activity) among students in 9th to 12th grade;
- reimmunization programs for the prevention of measles, mumps, and rubella in junior high and high school students;
- initiatives for injury prevention and control;
- activities to prevent or minimize complications for adolescents with diabetes;
- water fluoridation activities (not limited to adolescents);
- funding of the Southwest Center for Prevention Research at the University of Texas at Houston, focusing on the physical and psychological health of children and adolescents;
- support for the 1987 National Adolescent Student Health Survey, which assessed 8th and 10th grade students' knowledge, attitudes, and behaviors related to health (e.g., nutrition, alcohol and tobacco use, STDs, injury prevention, suicide, violence) (5);[19]
- National Health and Nutrition Examination Survey and the National Health Interview Survey, which incorporate nutrition and health data on adolescents (18);
- cooperative agreements with national, State, and local education agencies to implement HIV education for in- and out-of-school adolescents;
- adolescent health data collection by the National Center for Health Statistics;
- HIV seroprevalence surveys to determine the magnitude of infection within the adolescent population; and
- the phase of the "America Responds to AIDS" multimedia campaign targeting parents and youth.

The Centers for Disease Control appears to be spending most of its adolescent health-related money addressing health problems associated with sexual intercourse (e.g., pregnancy and the transmission of HIV and STDs). For example, although the mission of the Division of Adolescent and School Health is to identify, monitor the prevalence of, and implement interventions to reduce health risks[20] among adolescents, most of the Division's funding has been provided to prevent HIV infection. Therefore, its current priority area is to help schools develop effective educational programs to prevent the spread of HIV. On the other hand, in 1989 the Division of Injury Control within the Centers for Disease Control's Center for Environmental Health and Injury Control was allocated much less money, only \$3.27 million (approximately 15 percent of the Centers for Disease Control's injury budget), for the prevention and control of injuries among adolescents (e.g., youth suicide, homicide, and motor-vehicle related injuries), by far the largest killer of adolescents (24).

Health Resources and Services Administration—The Bureau of Maternal and Child Health (formerly the Office of Maternal and Child Health[21]), within the Health Resources and Services Administration, administers the maternal and child health block grant program authorized by Title V of the Social Security Act (see figure 19-6).[22] Eighty-five percent of the \$526.6 million appropriation for the program in fiscal year 1988 was allocated to States for

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[18] Proportion is based only on those agencies within the Centers for Disease Control responding to OTA's survey. These are the Division of HIV/AIDS, Division of Adolescent and School Health, Division of Reproductive Health, Division of Injury Control, Disabilities Prevention Program, and the Division of Sexually Transmitted Diseases and HIV Prevention. Several surveyed agencies did not provide adolescent-specific data.

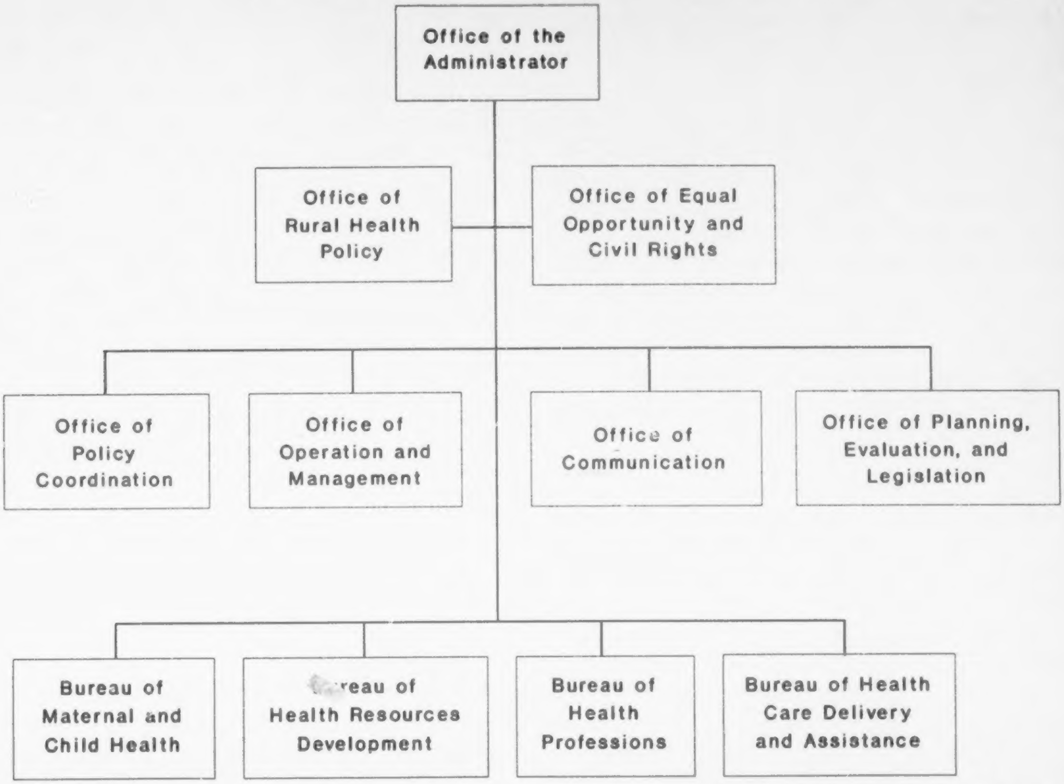
[19] The National Adolescent Student Health Survey was supported by the Office of Disease Prevention and Health Promotion within the Office of the Assistant Secretary of Health, with additional support from the Centers for Disease Control and the National Institute on Drug Abuse within the Alcohol, Drug Abuse, and Mental Health Administration.

[20] Priority risks are those behaviors resulting in unintentional and intentional injuries, alcohol and drug abuse, tobacco use, improper diet, insufficient physical activity, and HIV infection and other STDs.

[21] In May 1990, the Bureau of Maternal and Child Health and Resources Development split into two bureaus: the Bureau of Maternal and Child Health and the Bureau of Health Resources Development. When expenditures made prior to May 1990 are discussed here, the term "Office" will be used.

[22] Established in 1987, the Health Resources and Services Administration's Office of Rural Health Policy's role in rural adolescent health has been limited. The Office targeted adolescent suicide, pregnancy, and lack of access for health and mental health services in its Work Group on Health Services of the National Advisory Committee on Rural Health.

Figure 19-6—U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration


Office of the Administrator
Office of Rural Health Policy
Office of Equal Opportunity and Civil Rights
Office of Policy Coordination
Office of Operation and Management
Office of Communication
Office of Planning, Evaluation, and Legislation
Bureau of Maternal and Child Health
Bureau of Health Resources Development
Bureau of Health Professions
Bureau of Health Care Delivery and Assistance

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, organizational chart, no date.

programs to improve the health status of mothers and children, especially those with low incomes and living in areas with limited availability of health services (85).[23] [24] Approximately 21 States have a designated adolescent health care coordinator (16, 26).[25] [26]

Fifteen percent of the $526.6 million appropriation for the maternal and child health block grant program in fiscal year 1988 was set aside to support Special Projects of Regional and National Significance (SPRANS) (86).[27] In fiscal year 1988, 57 projects addressed the health needs of adolescents and children in various areas (e.g., research, training, genetics, hemophilia) (86). Twenty-three of these projects dealt specifically with injury prevention. In 1989, 36 projects[28] included adolescents specifically or as part of a larger group (26). Although no new projects targeting adolescents were begun in fiscal year 1990, approximately three new projects were scheduled to begin in fiscal year 1991 (16).

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[23] These State programs are sometimes called the Consolidated State Programs (86).

[24] In fiscal year 1987, States transferred over 30 percent of their maternal and child health block grant funds to local health departments (31).

[25] Information on the proportion of Title V maternal and child health services allocated specifically to adolescents is not available.

[26] The 21 are Arizona, Colorado, Connecticut, District of Columbia, Delaware, Florida, Hawaii, Iowa, Indiana, Massachusetts, Maine, Michigan, Mississippi, Minnesota, New Hampshire, Ohio, Oklahoma, Oregon, South Carolina, Washington, and Wisconsin (26). Preliminary survey results indicate that two or three more States may have such a coordinator (16). It is unclear how States are paying for adolescent health care coordinator positions. Because the position is typically located within a State's Office of Maternal and Child Health, it may be that many, if not most, States are funding the position with block grant funds (16).

[27] These projects are sometimes called Consolidated Federal Programs (86).

[28] Of these projects, 23 were demonstration projects, 7 were research related, and 6 were training projects (26).

The Health Resources and Services Administration's Bureau of Health Care Delivery and Assistance supports the provision of primary health care services to medically underserved populations by providing Federal funds for community and migrant health centers, as well as for comprehensive perinatal care programs for low-income women and children, health care for the homeless programs, and health care for substance abusers. In 1989, 814,000 adolescents received medical care in the community and migrant health centers; of these adolescents 117,000 females ages 10 to 14 received family planning services.[29] At least 121,000 adolescents received dental care. During 1988, the comprehensive perinatal care programs provided perinatal services to 6 percent of all U.S. pregnant adolescents under age 20 and to 29 percent of pregnant adolescents 15 years of age and under (1).

Indian Health Service—The Indian Health Care Improvement Act of 1976 (Public Law 94-437) gave funding to the Indian Health Service for a 7-year period to elevate the health status of American Indians and Alaska Natives. Recently, amendments (Public Law 100-713) to the Indian Health Care Improvement Act were passed that extended this funding. In fiscal year 1989, the Indian Health Service spent over $1.02 billion on health services (primarily clinical care for acute and chronic physical problems) to assist American Indians and Alaska Natives. No specific funds of the agency are allotted for adolescents, so it is difficult to assess the amount spent by the Indian Health Service on health care for adolescents.

In 1989, the Indian Health Service conducted an Adolescent Health Survey to obtain a database on adolescents for use in local programs. The Alcohol and Substance Abuse Programs Branch of the Indian Health Service funds three regional adolescent treatment centers for substance abuse, which cost a total of $2.4 million per year. The Indian Health Service also helps to support adolescent health centers in or near four schools in the Albuquerque, New Mexico area (44a).

In fiscal year 1989, the Indian Health Service targeted Indian adolescents as a priority group for prevention efforts, planning to specifically emphasize prevention of teen pregnancy, alcohol/substance abuse, mental health, violence, and suicide. However, only 7 percent of the *total* Indian Health Service budget was devoted to preventive health in fiscal year 1988 (44a).

National Institutes of Health—In fiscal year 1989, the various institutes and divisions of the National Institutes of Health spent $7.1 billion (8) to fulfill their mission of improving the health of individuals through advancement of the state of knowledge in biomedical science and health care (see figure 19-7).

Within the National Institutes of Health, the National Institute of Child Health and Human Development, established in 1963, is the institute most identified with behavioral and biomedical research on adolescent development (e.g., cognitive, emotional, and social development) and with research on reproduction, sexual behavior, the effects of nutrition on development, and patterns of adolescents' interaction with family, peers, and school (see table 19-4).[30]

In fiscal year 1988, the National Institute of Child Health and Human Development funded 147 projects (21). Between fiscal years 1980 and 1990, however, approximately 7 percent of the National Institute of Child Health and Human Development's budget was spent on research specific to adolescents (see table 19-3). In fiscal year 1990, the Institute estimated that $25.5 million will be spent on adolescents, focusing on the physiological, psychological, endocrinological aspects of puberty,[31] the nutritional needs of adolescents, adolescent pregnancy, and acquired immunodeficiency syndrome (AIDS) (21). As does the Division of Adolescent and School Health in the Centers for Disease Control, the National Institute of Child Health and Human Development places heavy emphasis on research dealing with adolescent sexual behavior and its consequences (see table 19-4).

Eight other institutes within the National Institutes of Health sponsor research that pertains to

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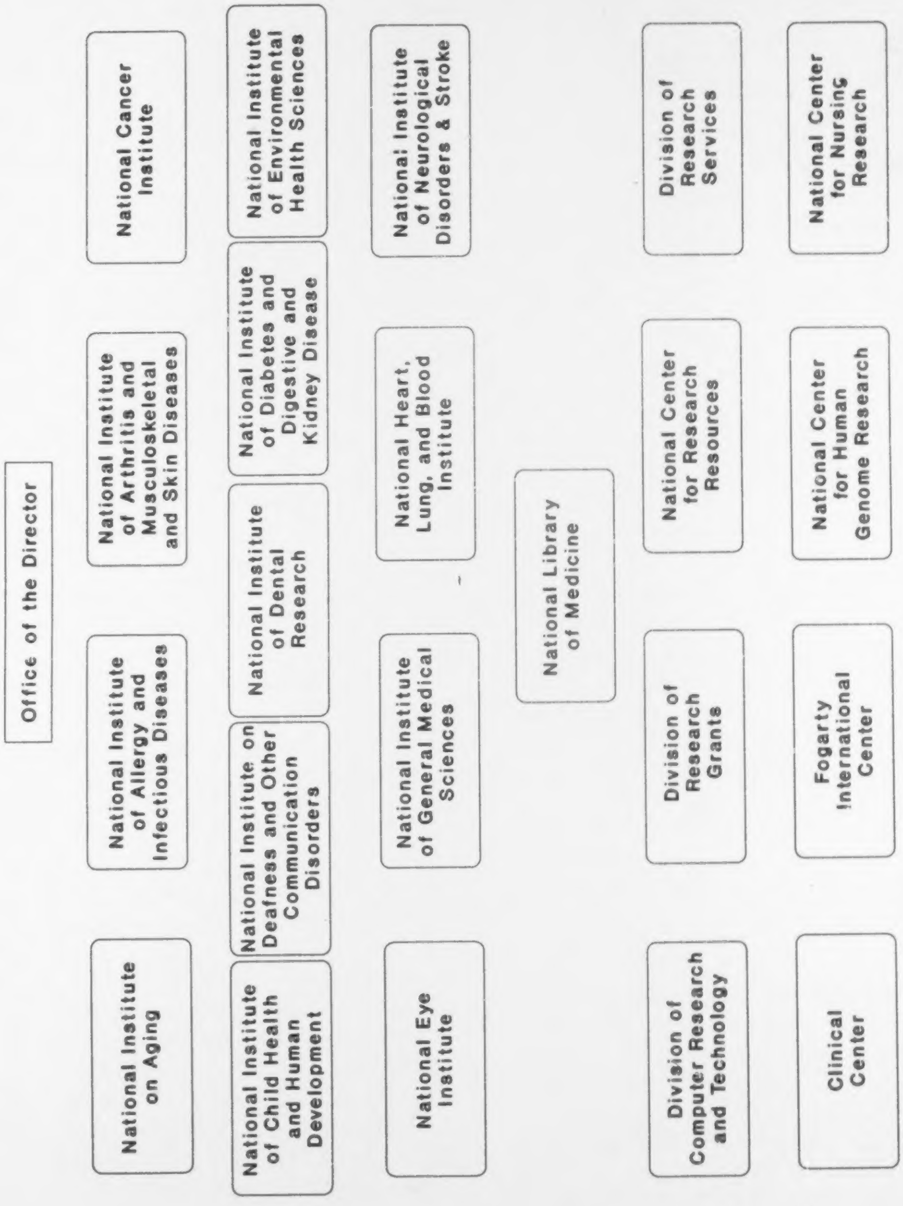
[29] The Bureau of Health Care Delivery and Assistance does not collect data on usage of community and migrant health centers by adolescents, ages 15 to 19. Data on this age group was collected eight years ago, but since then it has been discontinued.

[30] The National Institute of Child Health and Human Development does not deliver services to adolescents.

[31] Endocrinological aspects of puberty are those related to the functions of the endocrine glands (e.g., thyroid or pituitary gland).

Figure 19-7—U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health


Office of the Director
National Institute on Aging
National Institute of Allergy and Infectious Diseases
National Institute of Arthritis and Musculoskeletal and Skin Diseases
National Cancer Institute
National Institute of Child Health and Human Development
National Institute on Deafness and Other Communication Disorders
National Institute of Dental Research
National Institute of Diabetes and Digestive and Kidney Disease
National Institute of Environmental Health Sciences
National Eye Institute
National Institute of General Medical Sciences
National Heart, Lung, and Blood Institute
National Institute of Neurological Disorders & Stroke
National Library of Medicine
Division of Computer Research and Technology
Division of Research Grants
National Center for Research Resources
Division of Research Services
Clinical Center
Fogarty International Center
National Center for Human Genome Research
National Center for Nursing Research

SOURCE: U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, organizational chart, Bethesda, MD, no date.

Table 19-4—Adolescent Research Priority Areas of the Components of the National Institutes of Health

NIH agency	Adolescent research priority areas	Selected adolescent project descriptions
National Cancer Institute	Cancer prevention and control, improving the health of minorities and the underserved, and increasing patient accrual to clinical trials.	Smoking cessation interventions (e.g., school-based intervention research studies and a public information campaign to prevent adolescents from racial and ethnic minority groups from using tobacco); influence of smoking and drinking by families on Hispanic youth; adolescent v. adult diets on breast cancer risk; association of adolescent alcohol consumption, oral contraceptive use, dietary patterns, hormonal levels with breast cancer risk; school-based nutrition education project; adolescents' risk of developing leukemia; therapies for sarcomas; improving the survival of adolescent cancer patients through clinical studies by expanding eligibility criteria; improving adolescent cancer patients' psychological well-being (e.g., stress reduction, increasing school attendance).
National Center for Nursing Research	Nursing care of prospective mothers at risk of having low birth-weight babies, focusing on preventing pregnancy complications and care of low birth-weight babies. Prevention and physiological/psychosocial factors relating to the care of individuals with human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS).	Causes, consequences, and patterns of loneliness during adolescence; personality and environmental aspects of health compromising behaviors (e.g., cigarette smoking, drug and alcohol use, early sexual activity, eating behaviors, and excessive caffeine consumption) among young adolescents; improving communication within families of early adolescents using parenting styles and knowledge about adolescent and adult growth and development.
National Center for Research Resources	Does not set priorities in specific research areas as do the other institutes. The Center ensures availability of resources to the NIH community.	Hormonal aspects of growth and sexual maturation, psychosocial aspects of adolescence (e.g., effects of the government school breakfast program v. short-term fasting on adolescent cognition, behavior, and exercise; depression in adolescent males focusing on endocrine responses), diabetes and obesity (i.e., appropriate insulin levels), renal disease, urethritis, adolescent development using nonhuman primates, role of ethnicity in adolescent identity development, relationship of depression in children and adolescents, treatment program for adolescent substance abusers, aggressive conduct disorder, street youths' knowledge and attitudes toward AIDS prevention, history of immunization as a predictor of measles.
National Eye Institute	Research is not specifically targeted to adolescents.	Not provided
National Heart, Lung, and Blood Institute	Risk factors for cardiovascular disease, particularly hypertension, smoking, and blood cholesterol levels. Programs for adolescents with cystic fibrosis and sickle cell anemia.	Not provided
National Institute of Allergy and Infectious Diseases	Sexually transmitted diseases (STDs), AIDS, type I diabetes mellitus, asthma and allergy, chronic granulomatous disease.	Vaccine development for chlamydia, gonorrhea, syphilis, and herpes simplex virus type 2; diagnostic and therapeutic approaches for pelvic inflammatory disease and understanding the natural history of human papillomavirus; various aspects (e.g., epidemiologic and clinical) of individuals with AIDS, including prevention and treatment; mechanisms in the development of type I diabetes mellitus and chronic granulomatous disease; Self-Management of Asthma Educational Programs.

Continued on next page

Table 19-4—Adolescent Research Priority Areas of the Components of the National Institutes of Health—Continued

NIH agency	Adolescent research priority areas	Selected adolescent project descriptions
National Institute of Arthritis and Musculoskeletal and Skin Diseases	Systemic lupus erythematosus, particularly in minority populations, Lyme disease, juvenile arthritis, and osteoporosis (i.e., impact of diet and exercise during adolescence).	Pain treatment for adolescents with juvenile arthritis; psychological effects of pain on adolescents with juvenile arthritis; risk factors (e.g., diet, exercise, scoliosis development) during adolescence for the onset of osteoporosis.
National Institute of Child Health and Human Development	Physiological, psychological, and social consequences of adolescent pregnancy for mothers, their children, and other family members; endocrinological aspects of puberty, nutritional needs of the adolescent, and adolescent AIDS.	New contraceptives development (e.g., skin patch, implanted drug delivery system); preventing sexually transmitted diseases; understanding the transmission of HIV and its natural history in mothers and their children to prevent AIDS as well as developing age-appropriate educational strategies; investigation of the molecular basis for normal and abnormal male development and reproduction; role of genetics and environment (e.g., early family experiences) in development; female reproductive cycle disorders (e.g., pelvic inflammatory disease, severe premenstrual syndrome, interrelationship of nutrition and exercise with ovulation); sexual behavior and contraceptive use for contraception and disease prevention among adolescent females and their partners; consequences of adolescent childbearing; relationship between sexually transmitted diseases, including AIDS, and fertility-related behavior.
National Institute of Diabetes and Digestive and Kidney Diseases	Not planning specific initiatives on adolescent health.	Treatment of diseases (e.g., juvenile diabetes (insulin-dependent diabetes), cystic fibrosis, juvenile liver disease, inflammatory bowel disease, Cooley's and sickle cell anemia, hemophilia and growth abnormalities) often diagnosed and treated initially during adolescence.
National Institute of Neurological Disorders and Stroke	Head and spinal cord injury, stroke, juvenile epilepsy, lipid storage diseases, Tourette's syndrome, muscular dystrophies, autism, ataxias, Batten Disease, Reye's syndrome, tuberous sclerosis, learning disorders/attention deficit disorders, Charcot-Marie-Tooth syndrome, spinal muscular atrophies, juvenile myasthenia gravis, neurofibromatoses.	Incidence and duration of loss of consciousness in newly injured patients; natural history of adolescents following first epileptic seizure and risk factors for reoccurrence; development of skills (e.g., gestures) in developmentally disordered adolescents.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, unpublished data provided in response to the Office of Technology Assessment's questionnaire regarding adolescent health initiatives, 1989.

adolescent health. In general, their emphasis tends not to be related to adolescent sexual behavior but on various aspects of specific diseases. Although it is important to note that it is difficult for these institutes to disaggregate adolescent-specific research because of their disease-specific approach, the institutes were only able to identify a research budget of 2 percent ($114.93 million) that was clearly specific to adolescents in fiscal year 1989.

It appears that the National Institute of Allergy and Infectious Diseases places a greater emphasis on adolescents than do the other Institutes and divisions, including the National Institute of Child Health and Human Development. In fiscal year 1988, for example, the National Institute of Allergy and Infectious Diseases estimates that it spent approximately 15 percent of its overall budget on adolescents, as compared with only about 7 percent of the National Institute of Child Health and Human Development's budget. Like the National Institute of Child Health and Human Development, however, the National Institute of Allergy and Infectious Diseases primarily studies consequences of adolescent sexual behavior (i.e., STDs and AIDS).

Office of the Assistant Secretary for Health—Three agencies within the Office of the Assistant Secretary for Health are involved in matters related to adolescents and their health:

- the Office of Disease Prevention and Health Promotion,
- the Office of Minority Health, and
- the Office of Population Affairs (see figure 19-8).

Office of Disease Prevention and Health Promotion—Established by the National Consumer Health Information and Health Promotion Act of 1976 (Public Law 94-317), the Office of Disease Prevention and Health Promotion is responsible for supporting and coordinating prevention programs within the Alcohol, Drug Abuse, and Mental Health Administration, the Centers for Disease Control, the Food and Drug Administration, the Health Resources and Services Administration, and the National Institutes of Health (89).

The overall budget of the Office of Disease Prevention and Health Promotion in fiscal year 1989 was close to $5 million. Although the amount spent on adolescents is not known, the Office of Disease Prevention and Health Promotion has several ongoing activities that affect adolescents. Examples include awarding grants to national private sector organizations under the National Health Promotion Cooperative Agreements Program and the coordination of a broad-based public service initiative to develop the agenda for "Healthy People 2000: National Health Promotion and Disease Prevention." This initiative developed objectives targeted to adolescents.[32] The Office of Disease Prevention and Health Promotion has cooperative agreements with the Association of American School Administrators, as well as the American Medical Association to help promote the "Healthy People 2000: National Health Promotion and Disease Prevention" objectives as they relate to adolescents.

Office of Minority Health—The Office of Minority Health is the agency within DHHS which was originally established to be responsible for coordinating and monitoring the implementation of the recommendations from *The Report of the Secretary's Task Force on Black and Minority Health.* That report identified six health priority problem areas among minorities: cancer, cardiovascular disease and stroke, chemical dependency, diabetes, homicide and accidents, and infant mortality. In 1988, the Office of Minority Health added AIDS to the list of major health problems. Three major demonstration grant programs funded by the Office of Minority Health directly address the seven minority health priority areas. The Minority Community Health Coalition Program provides grants to develop community health coalitions which can effectively demonstrate risk reduction efforts among minority populations (91). In 1989, the Office of Minority Health awarded seven demonstration grants of approximately $200,000 each, two of which were directed at adolescent minorities. In addition, the HIV/AIDS Education and Prevention Grant Program awarded 24 grants of approximately $50,000 each in 1989 to both national and community-based minority organizations that provided education and information to minorities on the prevention of the spread of HIV (91). Three such grants on HIV/AIDS education and prevention directly affect adolescents (93). In 1990, the Office of Minority Health announce a three-part grant program to address the health and human service needs of

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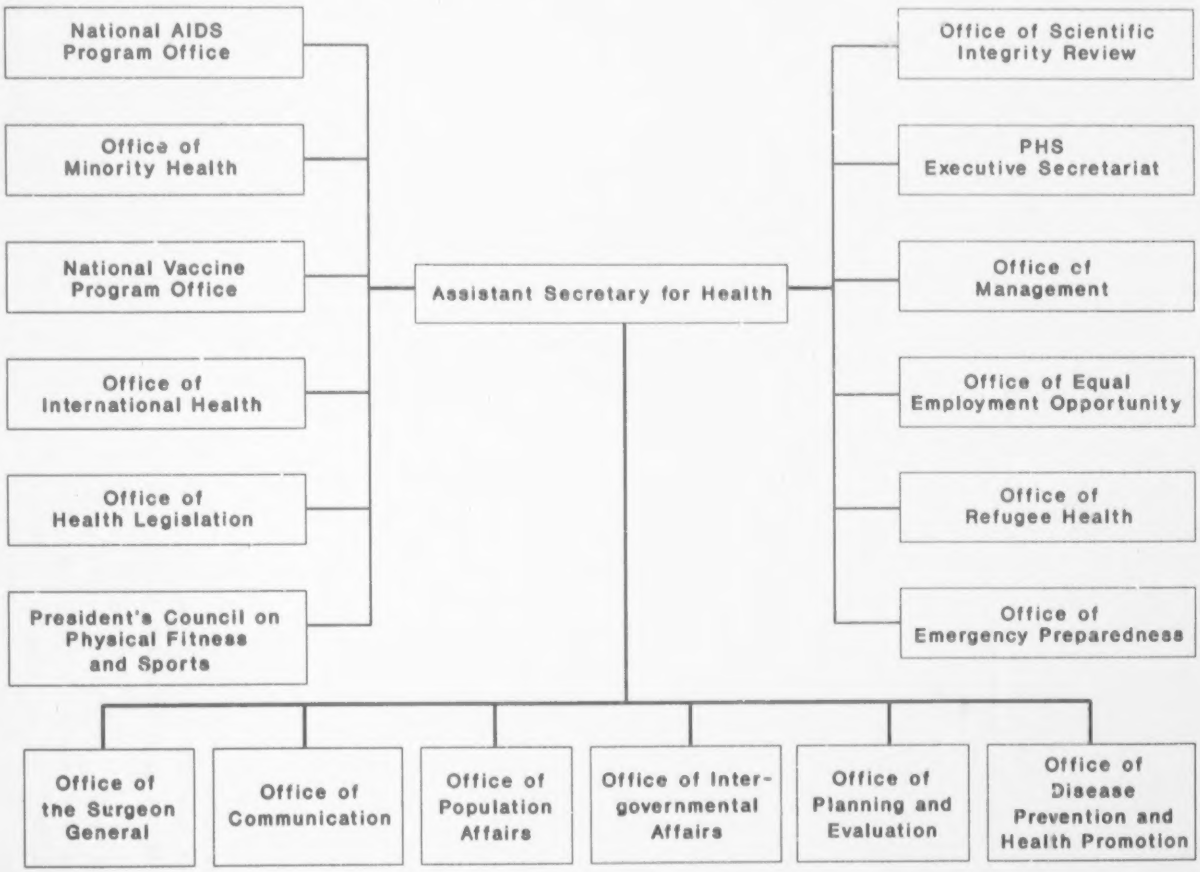
[32] Healthy People 2000 objectives pertinent to adolescents are discussed in *Volume I—Summary and Policy Options* of this Report (44b).

Figure 19-8—U.S. Department of Health and Human Services, Public Health Service, Office of the Assistant Secretary for Health


Assistant Secretary for Health
National AIDS Program Office
Office of Minority Health
National Vaccine Program Office
Office of International Health
Office of Health Legislation
President's Council on Physical Fitness and Sports
Office of Scientific Integrity Review
PHS Executive Secretariat
Office of Management
Office of Equal Employment Opportunity
Office of Refugee Health
Office of Emergency Preparedness
Office of the Surgeon General
Office of Communication
Office of Population Affairs
Office of Inter-governmental Affairs
Office of Planning and Evaluation
Office of Disease Prevention and Health Promotion

SOURCE: U.S. Department of Health and Human Services, Public Health Service, Office of the Assistant Secretary for Health, organizational chart, Washington, DC, 1990.

minority males of all ages. One program, funded at $450,000, was to support meetings and conferences on problems confronting high-risk minority males; a second, funded at $1.05 million, was to provide limited resources to plan and develop community coalitions to address the needs of high-risk minority males in specific communities; and the third, funding for which had not been announced, was intended to demonstrate methods of implementing community coalition intervention activities involving multiple organizations (55 FR 22312). In early 1990, a report by the U.S. General Accounting Office criticized the Office of Minority Health and later in 1990, the potential role of the Office was expanded when the U.S. Congress statutorily established such an Office, to be headed by a Deputy Assistant Secretary for Minority Health (Public Law 101-527, the "Disadvantaged Minority Health Improvement Act of 1990," section 2). Public Law 101-527 also authorized an increase in funding for the Office of Minority Health, to $25 million per year for fiscal years 1991 through 1993. The potential role of the Office in the health of minority adolescents is as yet unknown.

Office of Population Affairs—Within the Public Health Service's Office of the Assistant Secretary for Health, the Office of Population Affairs carries out activities related to adolescent pregnancy, family planning, and population research. The Office of Population Affairs has responsibility for administering Title X (Family Planning Services and Research Program) and Title XX (Adolescent Family Life Program) of the Public Health Service Act.[33]

The Office of Population Affairs provides Title X funds to public or private nonprofit organizations operating family planning projects for low-income families and encouraging family participation when possible. There are currently approximately 86 States, organizations, or independent family planning agencies receiving Title X moneys throughout the country (37). Services they provide include education, counseling, and medical services related to contraception as well as training for family planning personnel in general and nurse practitioners in particular to help improve the delivery of family planning services. Organizations which receive Title X money may not provide counseling and referral for abortion services except in medical emergencies.[34] In fiscal year 1990, $130 million was available for family planning service grants, 22 of which were awarded competitively (54 FR 35440); the remaining 64 awards represented continuations of projects which had competed in one of the prior 2 years. Current Title X priority areas are:

- the involvement of families of adolescent clients in Title X clinics,
- infertility services,
- natural family planning services,
- male involvement,
- sexually transmitted diseases,
- AIDS, and
- sexual abstinence for adolescents.

Approximately one-third of all Title X money is specific to adolescents. The last new reauthorization of funds for Title X was in 1984 (Public Law 98-512) (19). However, organizations continue to receive Title X funds through congressional appropriation acts.

The Office of Population Affairs provides Title XX (Adolescent Family Life Program) funds to support research and demonstration projects aimed at the alleviation, elimination, or resolution of negative consequences of adolescent premarital sexual intercourse. Specifically, abstinence from premarital sexual intercourse and adoption as an alternative to abortion are encouraged. Additionally, demonstration projects under the Adolescent Family Life Program attempt to establish innovative, comprehensive, and integrated health care services for pregnant and parenting adolescents under age 19. As with Title X funds, Title XX money cannot be used to provide abortions, abortion counseling, or abortion referrals, and adolescents must obtain parental consent before participating in any Title XX program (94). An average of 60 demonstration grants are funded under Title XX each year. In fiscal year 1986, Title XX demonstration projects served approximately 60,000 adolescents in both prevention and care programs. In addition, Title XX funds supported research on adolescent sexual activity and the effectiveness of available services. The funding for Title XX in 1990 was $9.5 million, all of which was for adolescents.

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[33] For a more in-depth discussion of services provided to pregnant and parenting adolescents by the Office of Population Affairs under Titles X and XX of the Public Health Service Act, see ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

[34] In a 5-4 decision on May 23, 1991, the U.S. Supreme Court upheld this regulation, despite the concern of some dissenting judges that the regulation "raises serious First Amendment [free speech] concerns" (*The New York Times*, "Excerpts From Court Ruling Curbing Family Planning Clinics," May 24, 1991, p. A19; L. Greenhouse, "Five Justices Uphold U.S. Rule Curbing Abortion Advice," *The New York Times*, p. A19, May 24, 1991).

Agencies Other Than DHHS: Programs and Expenditures for Adolescents

There are agencies other than those in DHHS that provide funding aimed at improving the lives of adolescents (see table 19-5). Many of these agencies, such as the U.S. Consumer Product Safety Commission and the U.S. Departments of Agriculture, Defense, Education, and Transportation, do not provide set-asides for adolescents but do include adolescents as a subgroup of larger populations served. Again, this factor makes determining expenditures for adolescents difficult.

ACTION

ACTION administers several Federal domestic volunteer service programs that provide human services to disadvantaged, poor, and elderly Americans.[35] Within ACTION, the Office of Domestic Operations administers several programs that affect adolescents. These include the Retired Senior Volunteer Program, the Foster Grandparent Program, Volunteers in Service to America (VISTA), the Student Community Service Program, and the Office of Program Demonstration and Development. The Foster Grandparent Program provides direct benefits (e.g., stipend, transportation, meal assistance, annual physical examination) to low-income individuals ages 60 and over who work 20 hours a week with children and adolescents with special needs (2). In fiscal year 1988, the Foster Grandparent Program sponsored 252 projects with a budget of $57.4 million. That year, it served about 70,000 young people, including about 25,500 ages 6 through 12 and 15,400 ages 13 through 20 (4). Typically, the young people assisted are at risk of drug or alcohol use, are in the delinquent detention system, are pregnant or parenting, or are mentally, physically, or emotionally disabled (2).

The VISTA program tries to help low-income people become self-sufficient by supporting projects sponsored by local public and private nonprofit organizations (2). In fiscal year 1988, 244 VISTA projects focused on youth (2). As of August 31, 1989, 66 VISTA volunteers were involved in 15 projects focusing on juvenile health, including the prevention of adolescent pregnancy, substance abuse, suicide, and violence (3). The Student Community Service Program funds projects that enable high school and college student volunteers to work as volunteers to help eliminate poverty-related problems. The estimated budget for the Student Community Service Program for fiscal year 1990 was $893,000 (7). In 1988, an estimated 28,000 students provided more than 850,000 hours of community service in various settings, such as Head Start programs, juvenile diversion programs, shelters, and soup kitchens (2).

The Program Demonstration and Development Division within the Office of Domestic Operations was created, in part, to award demonstration grants to organizations that have the potential to generate volunteer activity within a community and have the ability to serve as a model for other organizations. In fiscal year 1988, the Division awarded $2.6 million in demonstration and other grants for 79 projects (2).[36] Because Congress earmarked all fiscal year 1990 demonstration grants for illicit drug use prevention activities (7), ACTION gave top priority to drug prevention initiatives for at-risk youth in fiscal year 1990. These grants ($1.3 million for 1990), handled through the Office of Program Demonstration and Development's Drug Alliance Office, are awarded to community drug prevention projects that include enlisting volunteers from corporations to serve as mentors and organizing parent groups to prevent drug abuse.

U.S. Consumer Product Safety Commission

The U.S. Consumer Product Safety Commission typically does not focus on adolescents as an age group, but focuses on product-related hazards. For example, priority areas in fiscal year 1990 include indoor air quality, playground surfacing, diving injuries, choking hazards, and lead in water coolers. Although no projects are specifically aimed at adolescents, some projects do have a direct impact

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[35] The role of ACTION in organizing and coordinating domestic volunteer service activities may have been affected by passage in late 1990 of the National and Community Service Act of 1990 (Public Law 101-610). While the law intended to "build on the existing organizational framework of Federal, State, and local programs and agencies to expand full-time service opportunities for all citizens. . . .", it also established a Commission on National and Community Service to administer most of the programs established by the act. The programs established by the act are described briefly in *Volume I—Summary and Policy Options* and more fully in ch. 4, "Schools and Discretionary Time," in Vol. II.

[36] These projects were supported with $1.074 million in non-Federal contributions.

Table 19-5—Expenditures on Adolescent Health by Federal Agencies Other Than the U.S. Department of Health and Human Services

Agency with actual or potential role in adolescent health	Total expenditures (most current fiscal year)	Estimated expenditures for adolescents (most current fiscal year)	Percent of expenditures for adolescents
ACTION	$170,417,000 (1990)[a]	$16,127,000 (1990)[a]	9.4 percent
U.S. CONSUMER PRODUCT SAFETY COMMISSION	$34,500,000 (1989)	Not provided	Estimated at 50 percent for all children.
U.S. DEPARTMENT OF AGRICULTURE	Not provided	Not provided	Not provided
Extension Service	$361,370,000 (1989)	$90,342,500 (1989)[a]	25 percent
Human Nutrition Information Service	Not provided	Not provided	Not provided
Food and Nutrition Service	$21,264,955 (1989)	No specific line items for adolescents.	Not provided[b]
U.S. DEPARTMENT OF DEFENSE[c]	Not provided	Not provided	Not provided
Force Management and Personnel	Not provided	Not provided	Not provided
Office of Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)	$2,400,000,000 (1989)	$552,000,000 (1989)[a]	23 percent of CHAMPUS benefit costs are provided to adolescents ages 10 to 19.
U.S. DEPARTMENT OF EDUCATION	$22,467,400,000 (1989)	No specific line items for adolescents.	Not provided
Office of Planning, Budget, and Evaluation	Not provided	Generally, no specific line items for adolescents. Adolescents receive Federal money through funds provided to State and local educational agencies and other organizations.	Not provided
Office of the Assistant Secretary for Elementary and Secondary Education	$6,600,886,000 (1989)	No specific line items for adolescents.	Not provided
—Office of Indian Education	$71,553,000 (1989)	Not provided	Not provided
—Office of Migrant Education	$269,029,000 (1988)	$123,193,500 (1986-87)	45 percent
Office of the Assistant Secretary for Educational Research and Improvement	$78,200,000 (1989)	Not provided	Not provided
Office of the Assistant Secretary for Special Education and Rehabilitative Services	$3,558,500,000 (1988)	Not provided	Not provided
—Office of Special Education Programs	$2,109,982,000 (1988)	Not provided	Not provided
—National Institute on Disability and Rehabilitation Research	$53,525,000 (1989)	$17,461,006 (1989)[d]	32 percent
Office of the Assistant Secretary for Vocational and Adult Education	$1,080,614,000 (1989)	Not provided	Not provided
Office of Bilingual Education and Minority Languages Affairs	$197,394,000 (1989)	Not provided	Not provided
Office of the Assistant Secretary for Postsecondary Education	$5,814,320,000 (1989)	Not provided	Not provided
U.S DEPARTMENT OF JUSTICE	Not provided	Not provided	Not provided
National Institute of Justice	$21,000,000 (1989)	$4,200,000 (1989)[a]	20 percent
Office of Juvenile Justice and Delinquency Prevention	$72,482,000 (1990)	$72,482,000 (1990)	100 percent
U.S. DEPARTMENT OF LABOR	$24,900,000,000 (1990)	No line items specific for adolescents.	Not provided
Employment and Training Administration[e]	$3,728,431,000[f]	$2,166,367,000 (1989)[g]	58 percent
U.S. DEPARTMENT OF TRANSPORTATION	Not provided	Not provided	Not provided
Federal Highway Administration	$13,308,000,000 (1988)	No line items specific for adolescents.	Not provided
National Highway Traffic Safety Administration	$103,500,000 (1989)	$975,000 (1989)[a]	1 percent

[a] Estimated amount.

[b] Forty-three percent of the participants in the National School Lunch Program are in grades 7 through 12; 24 percent of those in the School Breakfast Program are in grades 7 through 12; 23 percent of those in the Summer Food Service Program are ages 13 to 18; 3 percent of those participating in the Supplemental Food Program for Women, Infants, and Children are pregnant, breastfeeding, or postpartum females less than age 18; and 34 percent of those in the Food Stamp Program are between the ages of 15 and 17.

[c] Questionnaire is from the perspective of the youth activities programs which are part of the Morale, Welfare, and Recreation Division. However, the Department's commitment to adolescents is not limited to these programs. Other agencies, such as Medical Programs, Mental Health Division, Drug and Alcohol Abuse Programs, and Chaplains Programs, sponsor activities for military youth.

[d] Adolescent projects are included within larger research efforts and are not specifically for adolescents.

[e] These data were obtained from E. Kolodny, U.S. Department of Labor (20).

[f] Funds are allocated for program year July 1, 1989—June 30, 1990 and not for the fiscal year (20).

[g] Forty percent of Title II-A, all of Title II-B, and all of Job Corps funding is allotted to youth, primarily ages 16 through 21 (20).

SOURCE: Office of Technology Assessment, 1990, based on Federal agency responses to the Office of Technology Assessment's survey on adolescent health, 1989.

on adolescents. These include projects related to all-terrain vehicles, fireworks, bicycles, lawn darts, water coolers with lead components, amusement rides, diving injuries, and playground surfacing. It is estimated that about 50 percent ($17.3 million) of the Commission's budget in fiscal year 1989 went toward activities that protected children[37] (40).

U.S. Department of Agriculture

Four of the U.S. Department of Agriculture Extension Service's nine priority areas include substantial adolescent components.[38] These initiatives are human nutrition, youth at risk, building human capital, and family and economic well-being. More specifically, building human capital involves helping adolescents develop self-confidence and the ability to think independently as well as helping communities accept adolescents as responsible and valuable members of society (45). Youth-at-risk research and demonstration projects include a model youth-at-risk program with the University of Arizona and adolescents as advocates for youth with Colorado State University. Within the Extension Service's 4-H program, adolescents ages 10 to 18 make up 66 percent of those individuals enrolled in the program, with 10- to 13-year-old adolescents making up 50 percent of those enrolled (45). In fiscal year 1989, approximately 25 percent of the Extension Service's budget of over $361 billion was dedicated to programs devoted to adolescent issues.[39]

The U.S. Department of Agriculture's Human Nutrition Information Service conducts and interprets applied research in food and nutrition (35). Other responsibilities include monitoring the food and nutrient content of diets, assessing dietary status and trends in food consumption, increasing understanding of the factors that influence consumer food choices, providing appropriate dietary guidance for the public, and developing techniques to help people make informed food choices.

The U.S. Department of Agriculture's Food and Nutrition Service administers several programs that provide food assistance to low-income individuals and families, including the Food Stamp Program, various child nutrition programs, and the Special Supplemental Food Program for Women, Infants, and Children (WIC) (22). Adolescents ages 15 to 17 make up an estimated 34 percent of the participants in the Food Stamp Program (22).[40] Child nutrition programs, such as the National School Lunch and School Breakfast Programs, and the Summer Food Service Program, provide food services to children and adolescents in public and nonprofit, private schools. Adolescents in grades 7 through 12 make up an estimated 24 percent of the participants in the School Breakfast Program and 43 percent of the participants in the National School Lunch Program (22).[41] Pregnant, breastfeeding, or postpartum adolescents make up an estimated 2.8 percent of WIC participants (22).

U.S. Department of Defense

The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) is a health benefits program provided by the Federal Government under public law primarily to dependents and retirees of the Air Force, Army, Coast Guard, Marine Corps, Navy, Public Health Service, and the National Oceanic and Atmospheric Administration (49). CHAMPUS covers residential treatment for certain mental disorders, family planning services,[42] general inpatient and outpatient care that is considered medically necessary, and general treatment for alcohol/drug abuse or dependency and detoxification, without complications or comorbidity. In addition, the Program for the Handicapped provides benefits for individuals, who are primarily adolescents, with moderate or severe mental retardation or serious physical disabilities. Under CHAMPUS, adolescents are covered if they are unmarried and under age 21, full-time students under age 23, or age 21 and over and severely disabled (49). In fiscal year 1989, $2.4 billion was spent on CHAMPUS (36).

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[37] The Consumer Product and Safety Commission does not specify what age groups this term encompasses.

[38] The priority areas are determined by executive and legislative directives with local and State input.

[39] Most projects are limited to a single year of funding.

[40] The Food Stamp Program supplements household income by improving families' food purchasing power.

[41] Participants are those children and adolescent students who ate a breakfast or lunch at least once during a week as determined by a 1-week survey (47).

[42] CHAMPUS covers measurement for contraceptive diaphragms and birth control pills but does not cover abortions except in very limited circumstances (49).

CHAMPUS estimates that approximately 23 percent of CHAMPUS benefit costs are provided to adolescents ages 10 to 19.

U.S. Department of Education

Generally, the U.S. Department of Education does not administer educational programs targeted specifically to adolescents but includes adolescents as part of the school-aged population. For example, the Education of the Handicapped Act programs provide special education and related services for children and adolescents with disabilities, and programs authorized by the Drug-Free Schools and Communities Act target high-risk youth, many of whom are adolescents. For most programs, counts of individuals served with U.S. Department of Education funds are done by grade level rather than by age.

In 1989, the Department had a budget of approximately $22 billion and was responsible for 187 programs spanning six different offices (figure 19-9). It is impossible to determine total adolescent expenditures, because U.S. Department of Education funds are distributed to State and local educational agencies that determine their own priorities. The U.S. Department of Education's own priority areas are determined through legislative mandates, reviews of current literature, and State-identified needs. Priorities include increasing educational services to economically and educationally disadvantaged children.

In terms of research and demonstration projects, the U.S. Department of Education programs are currently interested in dropout prevention, secondary education and transitional services for disabled youth, bilingual aid, compensatory education, Indian youth, homeless youth, and drug abuse prevention. Funding for compensatory education, Indian education, and education of homeless children and adolescents is estimated to account for 21 percent of the U.S. Department of Education's budget (34), but only selected programs could specify funds for adolescents.

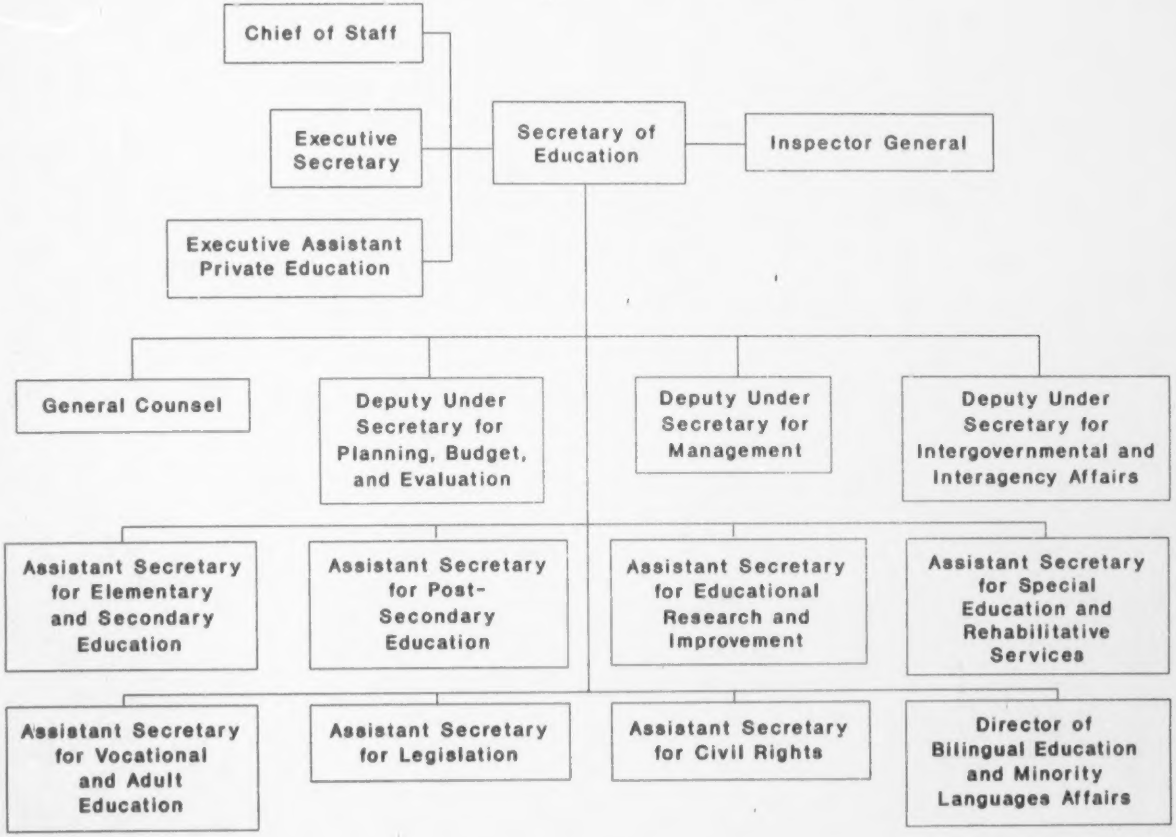
Within the Department, three offices fund more projects and activities for adolescents than do the others (table 19-5). These are the Office of the Assistant Secretary for Educational Research and Improvement, the Office of the Assistant Secretary for Elementary and Secondary Education, and the Office of the Assistant Secretary for Special Education and Rehabilitative Services.

Office of the Assistant Secretary for Educational Research and Improvement—Under the Secretary's Fund for Innovation in Education (Public Law 100-297), the Office of the Assistant Secretary for Educational Research and Improvement administers funds to both public and private institutions to improve health education for elementary and secondary students. In 1989, 18 projects were funded with approximately $3 million. The projects funded included various health education programs (on nutrition, fitness, disease prevention), State and local education reform models, and evaluations of health education programs. In 1990, $4 million was allotted to the Comprehensive School Health Education Programs, with a primary emphasis on models of health education programs and training needed to implement such programs (55).

Office of the Assistant Secretary for Elementary and Secondary Education—For the past two decades, the primary Federal vehicle for helping schools meet the educational needs of educationally disadvantaged children (i.e., children performing below their appropriate grade level, children of migrant workers, children with physical disabilities, and neglected or delinquent children under State care) has been the Grants for the Disadvantaged programs authorized by Chapter 1 of the Education Consolidation and Improvement Act of 1981 under the Office of the Assistant Secretary for Elementary and Secondary Education (53). In 1988, the Education Consolidation and Improvement Act was repealed and replaced by Title I of the Elementary and Secondary Education Act of 1965, enacted as part of the Augustus F. Hawkins-Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1988 (Public Law 100-297). The purpose of the amendment was to strengthen parental involvement and to improve access to high quality education for adolescents in areas with a high proportion of low-income families and for neglected or delinquent adolescents in State institutions (53,54 FR 21752).

The Office of the Assistant Secretary for Elementary and Secondary Education has one of the largest appropriations in the U.S. Department of Education, approximately $6.6 billion in fiscal year 1989 (56). Although the proportion allocated to adolescents cannot be precisely determined, major programs that provide adolescent-related efforts include the following:

Figure 19-9—U.S. Department of Education


Chief of Staff
Executive Secretary
Executive Assistant Private Education
Secretary of Education
Inspector General
General Counsel
Deputy Under Secretary for Planning, Budget, and Evaluation
Deputy Under Secretary for Management
Deputy Under Secretary for Intergovernmental and Interagency Affairs
Assistant Secretary for Elementary and Secondary Education
Assistant Secretary for Post-Secondary Education
Assistant Secretary for Educational Research and Improvement
Assistant Secretary for Special Education and Rehabilitative Services
Assistant Secretary for Vocational and Adult Education
Assistant Secretary for Legislation
Assistant Secretary for Civil Rights
Director of Bilingual Education and Minority Languages Affairs

SOURCE: U.S. Department of Education, organizational chart, Washington, DC, Sept. 15, 1989.

- Chapter 1 grants to provide financial assistance to State and local educational agencies to meet the special educational needs of disadvantaged children and adolescents;[43]
- education of homeless children and youth, as authorized by the Stewart B. McKinney Homeless Assistance Act;
- Indian education programs, as authorized by the Indian Education Act of 1988;
- training for elementary and secondary school teachers in math and science, as authorized by the Dwight D. Eisenhower Mathematics and Science Education, Hawkins-Stafford Amendments of 1988;
- migrant education program to address the educational needs of migratory agricultural workers and fishers ages 3 to 21, as authorized by Chapter 1 of Title 1 of the Elementary and Secondary Education Act of 1965;
- drug abuse education and prevention coordination in States and communities, as authorized by the Drug-Free Schools and Communities Act of 1986;
- dropout prevention demonstration projects conducted by local education agencies, educational partnerships, and community-based organizations to increase the number of children and adolescents remaining in school, as authorized by Title IV-A of the Elementary and Secondary Education Act of 1965 (56); and
- distribution of books to high school students under the Inexpensive Book Distribution Program to encourage adolescents to read, as authorized by the Education Consolidation and Improvement Act of 1981 and Chapter 2 of Title 1 of the Elementary and Secondary Education Act of 1965 (34).

Office of the Assistant Secretary for Special Education and Rehabilitative Services—Under the authority of Part B of the Education of the Handicapped Act (Public Law 94-142) and Chapter 1 of the Education Consolidation and Improvement Act as part of the Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35), the Office of Special Education Programs (within the Office of the Assistant Secretary for Special Education and Rehabilitative Services) supplies funds primarily to State education agencies to provide special education and related services to children and adolescents ages 3 through 21 with disabilities (57).[44] In 1987-88, a total estimate of $574.14 million or 44 percent of the total appropriation of approximately $1.3 billion was spent to reach close to 1.7 million students ages 12 to 17 (13).[45]

Under Chapter 1 Handicapped Programs (of the Education and Consolidation Improvement Act), State-operated programs provide special education to children and adolescents with disabilities who are in or have transferred from State-operated or State-supported programs. Over 83,000 students ages 12 to 17 received services through this program at an estimated cost of $48 million in the 1987-88 school year.[46]

One priority area within the Office of Special Education Programs is secondary education and transitional services for handicapped youth. This activity assists adolescents with disabilities and their families in making the adolescents' transition from secondary school to work life or postsecondary education settings. About $7.3 million was spent on this program in fiscal year 1988. Further, the Program for Severely Handicapped Children attempts to involve families in the planning and delivery of services and increase the number of children and adolescents with severe disabilities being served in regular school settings (54 FR 3945). Finally, the Office of Special Education Programs is supporting research projects for interventions to retain junior-high-school-aged students with disabilities, who are at risk of dropping out of school (54 FR 30642).

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[43] No age breakdowns are available for current funding of Chapter 1. However, in the 1987-88 school year, 21 percent (1,037,127) of the population served were students in grades 7 through 12 in both public and private schools, with funding for these adolescents totaling $3.8 billion (56).

[44] The Education of the Handicapped Act (Public Law 94-142) requires that all children and adolescents between the ages of 3 through 21 be served. However, States are not required to serve 3- to 5-year-olds or 18- to 21-year-olds if the service is inconsistent with State law or practice (57). Additionally, the statute requires that at least 75 percent of the funds must be passed through State education agencies to local education agencies and other agencies serving children directly. Up to 25 percent of the funds may be spent on direct and support services and administration at the State level.

[45] In fiscal year 1989, of the $2.1 billion appropriated to the Office of Special Education Programs, 93 percent of the funds ($1.94 billion) were awarded to State education agencies under five grant programs (57).

[46] In the 1987-88 school year, approximately 40 percent of children and adolescents with disabilities served were between the ages of 12 and 17. Most of these adolescents had learning disabilities (50).

Another branch of the Office of the Assistant Secretary for Special Education and Rehabilitative Services, the National Institute on Disability and Rehabilitation Research, administers a number of research activities that affect adolescents, although adolescents are not specifically targeted. For fiscal year 1989, $17.46 million was spent on initiatives that would affect adolescents. The priority areas for fiscal years 1989 and 1990 include research on children with severe emotional problems, a pediatric center for study of children's needs, spinal cord injury centers, and persons with orthopedic disabilities.

U.S. Department of Justice

Office of Juvenile Justice and Delinquency Prevention—The Office of Juvenile Justice and Delinquency Prevention was created under the Juvenile Justice and Delinquency Prevention Act (Public Law 93-415) and was authorized to administer programs and policies to improve the juvenile justice system, assist communities in responding to the needs of juveniles, assess the factors that contribute to juvenile delinquency, and inform practitioners about research findings and successful interventions (see figure 19-10). Additionally, the Office provides support and assistance to State and local juvenile justice agencies and delinquency prevention programs and facilitates cooperation and coordination among the Federal agencies funding juvenile delinquency programs. In fiscal year 1989, the office's budget was $66.69 million. The Office's fiscal year 1990 priorities are serious juvenile crime, illegal drug use, youth gangs, and missing and exploited children. Additionally, Congress mandated the following studies:

- determination of the extent to which confinement conditions in juvenile detention and correctional facilities comply with national standards;
- obstacles to legal custodians' recovery of children who have been removed by a noncustodial parent;
- village and tribal justice systems' treatment of American Indian and Alaska Native juveniles accused of committing crimes on or near reservations, and the availability of community-based alternatives to incarceration for these youth;
- extent to which minority juveniles are disproportionately detained or confined in secure juvenile detention or correctional facilities, jails or lockups; and
- improvement of national statistical data on juveniles taken into custody.

The Office of Juvenile Justice and Delinquency Prevention awards an estimated 115 to 120 discretionary grants each year, ranging from $15,000 to $4 million, with an average of approximately $215,000 per award in fiscal year 1989.[47] In 1988, Congress authorized that substantial portions of discretionary funds be shifted from discretionary to formula grants to States (34).[48] In fiscal year 1989, the funds allocated to States totaled $45.75 million.

National Institute of Justice—The National Institute of Justice within the U.S. Department of Justice works to improve the criminal justice system, addresses crime prevention and control, and enhances community safety and security. Although approximately 20 percent ($4.2 million) of the National Institute of Justice's overall budget of $21 million is spent on research and demonstration projects that include adolescent components, the National Institute of Justice generally does not target adolescents specifically. Its fiscal year 1990 priorities include examining drug marketing and associated crime, violent crime, effective policing strategies, white-collar and organized crime, and the prosecution and incarceration of offenders. Current adolescent projects include grants on drug use patterns of inner-city youth, drug testing of juvenile offenders, and helping fund the National Academy of Sciences Panel on Understanding and Controlling Violence which will examine adolescent data on violence. Additionally, the program of research on Human Development and Criminal Behavior will examine developmental factors that influence delinquency, crime, and other antisocial behavior.

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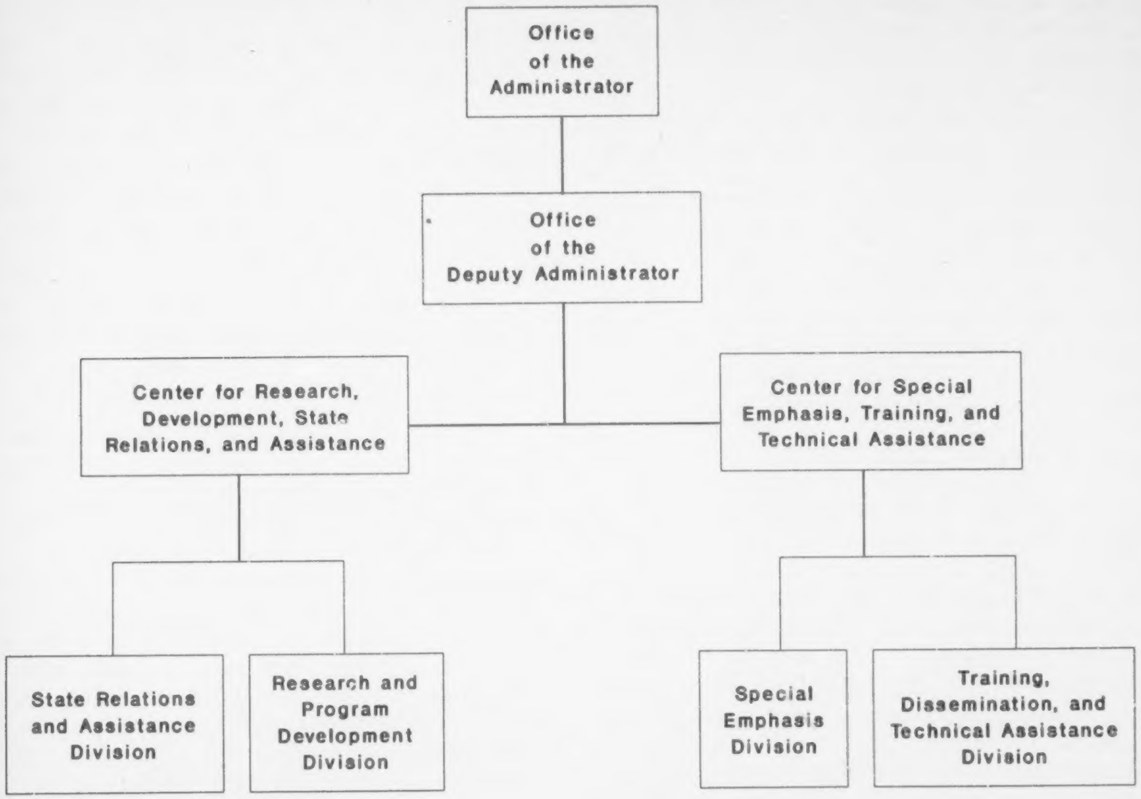
[47] In fiscal year 1988, 86 initiatives were funded, including 24 on illegal drug use, 18 on missing and exploited children, 6 on violence in the schools, and 3 on juvenile gang violence (97).

[48] In order to be eligible for these grants, States must comply with section 223(a)(12)(A)(13) and (14) of the Juvenile Justice and Delinquency Prevention Act requiring the deinstitutionalization of status offenders and nonoffenders, the separation of juveniles from adults within secure confinement facilities, and the removal of juveniles from adult jails and lockups.

Figure 19-10—U.S. Department of Justice, Office of Juvenile Justice and Delinquency Prevention


Office of the Administrator
Office of the Deputy Administrator
Center for Research, Development, State Relations, and Assistance
Center for Special Emphasis, Training, and Technical Assistance
State Relations and Assistance Division
Research and Program Development Division
Special Emphasis Division
Training, Dissemination, and Technical Assistance Division

SOURCE: U.S. Department of Justice, Office of Juvenile Justice and Delinquency Prevention, *Twelfth Analysis and Evaluation: Federal Juvenile Delinquency Programs 1988* (Washington, DC: 1988).

U.S. Department of Labor

Within the U.S. Department of Labor, the Employment and Training Administration is the agency most directly supporting activities affecting adolescents. In program year 1989, funding for youth was estimated to account for 58 percent ($2.2 billion) of the budget. Employment and Training Administration projects for youth typically focus on adolescents and young adults ages 16 and over. The Employment and Training Administration supports employment and training programs for economically disadvantaged youth under the 1982 Job Training Partnership Act. Three sections of the Job Partnership Training Act affect adolescents ages 16 to 21: Titles II-A, II-B, and IV.

Titles II-A and II-B of the Job Training Partnership Act authorize block grants to States. Under Title II-A, training services are offered throughout the year to economically disadvantaged adults and youth. Forty percent ($715.1 million) of the total budget in program year 1989 for Title II-A was earmarked for adolescents.[49] Title II-B establishes a summer employment program for low-income youth. All of the funding for Title II-B, $709.4 million for summer 1990, was designated for adolescents, and $12.9 million of this total was used to support summer employment opportunities for Native American youth (99).

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[49] States are required to allocate funds according to a set formula, so that 78 percent of the funds are distributed to service delivery areas (designated by Governors) and the remaining 22 percent is for State set-asides.

Title IV authorizes various federally administered programs affecting adolescents, such as Job Corps and programs designed for Native Americans and migrant workers. Job Corps, a joint venture between the U.S. Department of Labor, private corporations, and nonprofit organizations, provides employment and training in primarily residential centers for disadvantaged adolescents and young adults ages 16 to 21 (100). The U.S. Department of Labor provides funding for the centers, which totaled $741.8 million in program year 1989, and corporations and nonprofit organizations organize and manage the centers under a contractual agreement. In program year 1989, there were 100,000 participants in Job Corps. After completing the program, 66.9 percent of the participants were placed in jobs and 16.7 percent went on for further education.

In addition, Title IV establishes funding for research, which is administered by the Division of Research and Demonstrations in the Office of Strategic Planning and Policy Development. One of the primary goals is to address the problem of unemployed youth or those at risk of becoming unemployed. Specific programs include grants for the following: to integrate Federal, State and local services; to investigate patterns of youth achievement; to link school and employment with apprenticeships; to evaluate demonstrations providing alternative education to at-risk youth; and to analyze interagency demonstrations (98). Currently, 35 such research projects are underway, and the average cost per project is approximately $275,000.

Under the Employment and Training Administration's Office of Work-Based Learning, the Bureau of Apprenticeship and Training administers various apprenticeship programs authorized by the National Apprenticeship Act of 1937. Federal staff from the Bureau of Apprenticeship and Training, as well as State personnel in some States, assist in providing technical assistance to the apprenticeship programs, which are sponsored by industry. The average age of most apprentices is about 29, and about 17 percent of apprentices are between the ages of 16 and 22 (25). There is one type of apprenticeship program designed specifically for adolescents. The School-to-Apprenticeship Program, which makes up less than 1 percent of all apprenticeship programs, provides adolescents with the opportunity to attain valuable job skills in an apprenticeship when they are high school seniors (101).

U.S. Department of Transportation

Federal Highway Administration—The Federal Highway Administration does not typically target individuals of any age group, but supports programs, such as highway repairs and maintenance, which improve the safety of the roads for everyone. Within the Federal Highway Administration, however, the Office of Highway Safety sponsors a number of research and demonstration projects that indirectly affect both adolescent drivers and pedestrians. For fiscal years 1987-91, $10 million was allocated for safety research and development, which includes research on accidents among young drivers, pedestrians, and bicyclists (102).

National Highway Traffic Safety Administration—Although the National Highway Traffic Safety Administration does not have any adolescent-specific priorities for fiscal years 1989 and 1990, the agency does fund several programs that include adolescents. Because motor vehicle accidents are the greatest cause of death for adolescents and young adults ages 15 to 24, this age group is targeted by the National Highway Traffic Safety Administration. Activities for adolescents and young adults under age 21 include alcohol and drug accident prevention, passenger protection, and motorcycle safety; these activities take place in a variety of settings, such as schools, offices, and other places in the community. In addition, within the National Highway Traffic Safety Administration, the Office of Traffic Safety Programs has formed a Youth Committee to coordinate its highway safety activities for young adults. The National Highway Traffic Safety Administration also supports workshops in colleges and media announcements dealing with alcohol and drug and highway safety policies. Research priorities include accident prevention techniques for use by States and communities.

The National Highway Traffic Safety Administration also funds activities aimed at individuals younger than age 15, which primarily affect adolescents in the 10- to 14-year-old age group. These activities include pedestrian safety programs, a bicycle education program, dissemination of educational kits for schools and communities, and informational guides related to car air bags, alcohol, and safety belt use. As an example, "The Car Club," an instructional kit for junior high and middle school students, provides information on car occupant protection.

In 1989, the National Highway Traffic Safety Administration programs were estimated to reach over 30 million elementary, junior high, and high school adolescents. But in 1989, less than 1 percent ($975,000) of the Administration's budget was estimated to target adolescents. Estimates for research programs targeting adolescents are not available; however, total research funding is estimated at $775,000 for 1989.

Coordination at the Federal Level

Currently no one agency, department, or executive office formally coordinates Federal activities related to adolescents, but some coordination does take place within and between organizations in the form of committees and memoranda of agreement.[50] For example, within the Alcohol, Drug Abuse, and Mental Health Administration, the National Institute on Alcohol Abuse and Alcoholism and the National Institute on Drug Abuse together fund grants for drug and alcohol abuse prevention research. The U.S. Department of Justice's National Institute of Justice and the Office of Juvenile Justice and Delinquency Prevention fund a project on Drug Use Patterns of Inner City Youth. Examples of current efforts between agencies are listed below.

- The Ad Hoc Committee on Health Promotion Through the Schools, which is coordinated through the Office of Disease Prevention and Health Promotion and involves about 10 Federal agencies (e.g., U.S. Environmental Protection Agency, the Indian Health Service, Bureau of Maternal and Child Health, and the U.S. Departments of Agriculture, Defense, Education, Health and Human Services, and Transportation) (14).
- The multi-agency collaboration with the Centers for Disease Control's Division of Adolescent and School Health in the development of a Youth Risk Behavior Surveillance System.
- The Coordinating Council of Juvenile Justice and Delinquency, created by Section 206 of the Juvenile Justice and Delinquency Prevention Act, coordinates Federal juvenile delinquency programs[51] and is composed of cabinet-level representatives from 18 member Federal agencies. In fiscal year 1988, Coordinating Council agencies supported 72 initiatives to prevent juvenile delinquency (97).
- The Ad Hoc Federal Interagency Working Group, which was developed to bring about a more coordinated governmental response to the drug problems within individual communities. Agencies include the National Highway Traffic Safety Administration, and the U.S. Departments of Education, Health and Human Services, Housing and Urban Development, Justice, and Labor.
- The Interagency Panel on Children and Adolescents meets monthly to share information and coordinate research efforts on issues affecting children and adolescents. Member agencies report on current research, demonstration projects and various programs; in addition, they discuss interagency joint research. The panel

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[50] In April 1991, the Secretary of Health and Human Services announced a reorganization of some DHHS programs for children and families within DHHS (61a). The purpose of the reorganization was "to place greater emphasis and greater focus on the needs of America's children and families" (61a). The reorganization would combine all programs of the Family Support Administration and the Office of Human Development Services, and the maternal and child health block grant program in the Health Resources and Services Administration of the Public Health Service, into a new "Administration for Children and Families." The new Administration for Children and Families would be on an equal level with the Public Health Service, the Health Care Financing Administration, and the Social Security Administration. Programs in the new operating division would include programs such as Head Start, Job Opportunities and Basic Skills, Aid to Families With Dependent Children, Child Support Enforcement, Adoption Assistance, Foster Care, the Social Services Block Grant, Child Care and Development Block Grant, and child abuse programs, as well as the maternal and child health block grant (61a). The combined budget of the new Administration was estimated by DHHS to be $27 billion and the size of the staff 2,000. According to the announcement, no funding or staff cuts will take place as a result of the change. Although the reorganization was said to be effective immediately, the DHHS announcement indicated that the change will involve extensive followup implementation. Consequently, a task force to direct the implementation had been formed (61a). Thus, although one of the intended divisions of the new Administration for Children and Families was an office of "Children, Youth and Families," the role of adolescent health issues in the new Administration was not immediately clear. It is important to note that many of the approximately 60 U.S. executive branch agencies with a role in adolescent health (some of them in departments other than DHHS; see figure 19-1) were not included in the reorganization.

[51] Coordination occurs among the U.S. Department of Justice [National Institute of Justice and the Office of Juvenile Justice and Delinquency Prevention], U.S. Department of Health and Human Services [Administration for Children, Youth and Families; Family and Youth Services Bureau; Office of Community Services; Alcohol, Drug Abuse, and Mental Health Administration], U.S. Office of National Drug Control Policy, U.S. Department of Education, U.S. Department of Transportation [National Highway Traffic Safety Administration], U.S. Department of Labor, U.S. Department of the Interior [Bureau of Indian Affairs], U.S. Department of Housing and Urban Development, ACTION, and the U.S. Environmental Protection Agency (97).

also conducts an annual conference to discuss topics in depth, inviting experts from outside the Federal government. Twenty-eight government agencies are represented at the monthly panel meetings. Agencies include ACTION and the U.S. Department of Agriculture, Defense, Education, Health and Human Services, Justice, Labor, State, and Transportation (12).

Examples of past and current Memoranda of Agreement follow:

- Parent education to low-income parents (including adolescents), expectant parents, and care givers of children ages 0 to 36 months in at-risk families: Office of Human Development Services, U.S. Department of Health and Human Services; Extension Service, U.S. Department of Agriculture;
- Community-based mental health services for youth: National Institute of Mental Health, Alcohol, Drug Abuse, and Mental Health Administration; Bureau of Maternal and Child Health, Health Resources and Services Administration;
- Assignment of medical students to youth shelters to help enhance coordination of health services: Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration; Office of Human Development Services, U.S. Department of Health and Human Services;
- Demonstration projects in consumer education for public housing residents on nutrition and decisionmaking in eight sites: U.S. Department of Agriculture, Extension Service's 4-H Youth Development Program; U.S. Department of Housing and Urban Development; Kraft General Food Foundation (48);
- Support for the Cities in School project: U.S. Department of Health and Human Services, U.S. Department of Labor, U.S. Department of Justice, U.S. Department of Education;
- Programs for American Indian youth related to alcohol and drug abuse education and prevention services for Indian children and adolescents attending elementary and secondary schools on reservations: U.S. Department of Education, U.S. Department of the Interior (14);
- Supporting and mobilizing national resources for young children and youth with HIV infection and AIDS-related complex: Office of Human Development Services, U.S. Department of Health and Human Services; Public Health Service, U.S. Department of Health and Human Services;
- Conducting 1988 National Health Interview Survey's Child Health Supplement; National Health and Nutrition Examination Survey III Child Health Component: National Center for Health Statistics, Centers for Disease Control; Health Resources and Services Administration;
- Conducting National Adolescent Student Health Survey: Centers for Disease Control; National Institute on Drug Abuse, Alcohol, Drug Abuse, and Mental Health Administration; Office of Disease Prevention and Health Promotion, Office of the Assistant Secretary for Health;
- National Longitudinal Survey of Youth: U.S. Department of Labor; U.S. Department of Defense; National Institute of Child Health and Human Development, National Institutes of Health; National Institute on Alcohol Abuse and Alcoholism and National Institute on Drug Abuse, Alcohol, Drug Abuse, and Mental Health Administration (30);
- Plan and implement cooperative program activities related to the provision of services, education, and treatment to pregnant and postpartum women and to infants in the area of drug abuse prevention, education, and treatment via women in the Special Supplemental Food Program for Women, Infants, and Children (WIC) program: Office for Substance Abuse Prevention, Alcohol, Drug Abuse, and Mental Health Administration; Food and Nutrition Service, U.S. Department of Agriculture;
- Market research study conducted by S.W. Morris & Co. to determine what high-risk adolescents know about certain issues, such as AIDS, teenage pregnancy, and substance abuse, and how they received this information: Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services; U.S. Department of Education; U.S. Department of Justice; U.S. Department of Transportation (29);
- Demonstration grant program to develop model programs for pregnant and postpartum women (including adolescents) and their infants: Office for Substance Abuse Prevention, Alcohol, Drug Abuse, and Mental Health Administra-

tion; Bureau of Maternal and Child Health, Health Resources and Services Administration;

- Supporting the reduction of crime in schools, Drug Prevention Education in the Schools, and D.C. Drug Free School Zone (Z-1000) Program: Office of Juvenile Justice and Delinquency Prevention, and National Institute of Justice, U.S. Department of Justice; U.S. Department of Education (54);
- Children in Custody Census of Juvenile Detention, Correctional and Shelter Care Facilities: Office of Juvenile Justice and Delinquency Prevention, and National Institute of Justice, U.S. Department of Justice; Bureau of the Census;
- Wilmington Delaware Public Housing Initiative: Office of Juvenile Justice and Delinquency Prevention, and National Institute of Justice, Bureau of Justice Assistance, U.S. Department of Justice; U.S. Department of Housing and Urban Development;
- Supporting programs on military installations: Extension Service, U.S. Department of Agriculture; U.S. Department of Defense;
- Improve breastfeeding promotion: Food and Nutrition Service, U.S. Department of Agriculture; Office of Maternal and Child Health, Health Resources and Services Administration, in the U.S. Department of Health and Human Services;
- Identification of ways to integrate food assistance services into migrant health care programs: Food and Nutrition Service, U.S. Department of Agriculture; Migrant Health Programs;
- Smoking Cessation in Pregnancy demonstration project: Food and Nutrition Service, U.S. Department of Agriculture; Centers for Disease Control, U.S. Department of Health and Human Services;
- Facilitating the transfer of nutrition education to American Indian households: Food and Nutrition Service, U.S. Department of Agriculture; Indian Health Service, Public Health Service, U.S. Department of Health and Human Services;
- Cooperation on bicycle safety issues: U.S. Consumer Product Safety Commission; National Highway Traffic Safety Administration, U.S. Department of Transportation.

In addition, some Federal agencies have become involved in promoting coordination at the local level. These efforts include the following:

- Division of Children, Youth, and Families within the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services.

  The Division has undertaken a study that will evaluate the feasibility of reorganizing local existing social services for at-risk children, youth, and families into a comprehensive community-based system. This effort, funded at $135,000, ties into local initiatives sponsored by the Annie E. Casey Foundation.
- Regional Offices of the Employment and Training Administration within the U.S. Department of Labor and the U.S. Department of Health and Human Services.

  These offices coordinate Youth 2000, a project designed to mobilize local efforts to address problems with at-risk youth, including illiteracy, incompletion of high school, teenage pregnancy, and alcohol and drug abuse (98).
- Child and Adolescent Service System Program within the National Institute of Mental Health.

  The Child and Adolescent Service System Program tries to promote change in the ways in which communities and States deliver health services to severely emotionally disturbed children. Two Research and Training Centers under the Child and Adolescent Service System Program are funded through an interagency agreement with the U.S. Department of Education's National Institute on Disability and Rehabilitation Research, and a Technical Assistance Center is funded through an agreement with the Health Resources and Services Administration's Bureau of Maternal and Child Health and Resources Development (76).
- High Risk Program within the Child and Family Support Branch of the National Institute of Mental Health.

  The High Risk Program is helping to integrate HIV-infected children and adolescents into State service networks for children and adolescents with severe emotional disturbance (78).

Additionally, several agencies have agreements with private businesses. For example, through the national Cooperative Extension System, the U.S. Department of Agriculture and professionals at land-grant universities are trying to extend research and technology into the communities (45). Additionally, discussions are being conducted with the U.S. Department of Housing and Urban Development's Division of Indian and Low Income Housing, the U.S. Department of Agriculture's Extension Service, and private industry to target youth programs in selected locations of high-risk factors.

A common theme among the reports reviewing Federal policies toward children and adolescents and among representatives at OTA's meeting with representatives of U.S. executive branch agencies with a role in adolescent health is the need for leadership and coordination at the Federal level, although the mechanism to provide for this coordination is not uniformly agreed upon.

In 1980, a report from the National Commission on Youth recommended the development of a comprehensive national youth policy at the Federal level to serve the needs of all young persons rather than targeted segments of the population (26a). Furthermore, the Commission suggested that the policy should be long-term with a startup period to build experienced personnel for program supervision. In addition, the Commission recommended both a presidential commission to study youth problems and the establishment of a White House youth office to coordinate policies and programs.

Given the gaps in and between adolescent services, fragmentation and duplication in both programs and services, and conflicts among various levels of government and among a variety of programs, the 1981 report *Better Health for our Children* (96) recommended that an Administration on Maternal and Child Health be created that would have a broad role in coordinating programs for youth and children.

In 1988, the National Commission to Prevent Infant Mortality recommended that a permanent national council on children's health and well-being be established to provide coordination and collaboration among Federal agencies to promote the health of both pregnant women and children (27).

In both 1987 and 1989, the W.T. Grant Foundation stated that the Federal Government has not provided a "coordinated, comprehensive direction for youth" ages 16 through 24 (33,34).

Most recently, the Institute of Medicine reviewed the level of implementation of recommendations by over 20 major commission and panel studies on children, youth and families published between 1983 and 1988. The review, *Social Policy for Children and Families*, noted that "there is no entity taking responsibility or catalyzing the nation into action. No coordinating mechanisms exist to ensure that the necessary services are provided effectively and efficiently to those in need. . . .[There is] no public leadership on children's issues" (28). The history of the Children's Bureau provides an illuminating example of the way Federal policy on children and youth has developed in the past (see box 19-A).

Most of these reports have not distinguished between children and adolescents. The Federal agency representatives who came to OTA for discussion in October 1989 agreed that there was little coordination on adolescent issues. Some of the responsibility for the isolation and fragmentation these representatives experienced was attributed to the legislation that guides executive branch programs. In fact, the fragmentation of services may be due in part to the many authorizing congressional committees from which agencies take direction (table 19-6). As just one example, 53 House committees and subcommittees and 21 Senate committees and subcommittees exercise some jurisdiction over controlling drug use in the general population (41). Still, the U.S. Executive Branch representatives did not believe that an agency devoted specifically to adolescent issues would be the preferred method to improve adolescent health, especially in these times of fiscal restraint. They favored incentives to increase cooperation and coordination among the current Federal agencies.

Conclusions and Policy Implications

The response to OTA's August 1989 survey of Federal agencies suggest that many Federal agencies support a range of activities directed toward improving the health of adolescents. As reflected in Federal agency budgets, however, adolescent health issues generally do not receive much emphasis. Among DHHS agencies, for example, it is rare for an agency to devote more than 10 percent of its expenditures specifically to adolescents (see table 19-3). DHHS agencies responding to OTA's survey that do devote more than 10 percent of their expenditures to adolescents were the Centers for Disease Control's Division of Adolescent and School Health (100 percent), the Health Resources and Services Admin-

Box 19-A—History of the Children's Bureau

The idea of a central coordinating body for programs and policies related to children and youth in the United States is not new. The Children's Bureau was established in 1912. The issues surrounding the development of the Bureau are not at all dissimilar to some of the issues facing the Nation today.

In the late 1800s, with the rapid growth of industrialization and migration to cities, communities were faced with a lack of foster care for abandoned children, high infant mortality rates, problems of gangs of homeless youth roaming the streets, juvenile delinquency, education, and child labor. It was becoming more and more critical that both national and local policies relating to children be developed. There was also the need for more accurate information on the condition of children.

The editors of a multi-volume history of children and youth in America noted that the Children's Bureau was:

> The single most important development in the public provision of services to children during the early 20th century. . . The founding of this agency signified acceptance by the Federal government of responsibility for promoting health and welfare of the young. The Bureau was not organized as a research and information center and did not initially perform any child welfare services. Its function was to investigate and report upon all matters pertaining to the welfare of children and child life among all classes of our people including questions of infant mortality, the birth rate, orphanage, juvenile courts, desertion, dangerous occupation, accidents and diseases of children, employment, and legislation affecting children in the several states and territories (10).

Grace Abbott, a former director of the Children's Bureau, noted that "the whole child was made the subject of the research." The interrelated problems of child health, dependency, delinquency, and child labor were to be considered and interpreted in relation to the community program for all children" (10). This theme is one heard time and again in relation to the health problems of today's adolescents.

The development of the Children's Bureau from its initial conception in 1903 until it was signed into law in 1912 was not without controversy. The themes expressed by opponents of the Bureau seem remarkably familiar today. Opposition to the 1909 bill was in part based on the view that such a bureau would be unconstitutional as it purported to exercise jurisdiction over State and local agencies concerned with child welfare. It was also felt that such programs in the Children's Bureau would be duplicative of efforts by either the Department of Census or the Department of Education. Surprisingly, opposition was also expressed by the New York Society for the Prevention of Cruelty to Children which felt that the Bureau would "inevitable interfere with the work of our Societies where they exist through the entire United States" (10). One senator speaking out against the Bureau noted that ". . .While upon the face of this measure it merely provides for the taking of statistics, the accumulation of knowledge, yet we know from other measures which have been introduced, some from the same source, that it contemplates the establishment of a control, through the agencies of government, over the rearing of children" (10).

Despite these objections, a Children's Bureau was signed into law. In its first 10 years, the activities of the Bureau resulted in an increase in the number of States with special units concerned with child health from 1 to 46. Some of the issues brought to the fore by the Children's Bureau and local bureaus again are germane today. A report in 1927 by the Children's Bureau of Cleveland indicated that ". . .no other dependency of children is so great a tax on the financial resources and on the skill of the staffs of social welfare agencies as that of divorce, separation and desertion. The difficulties in families broken by divorce or desertion are so complex that the work of medical and social agencies of community must be well coordinated in order to salvage as many of these wrecked families as possible" (10).

In 1934, a report by the Bureau to the Committee on Economic Security on the impact of the depression noted that ". . .among adolescents were found evidences of increasing mental instability and inability to meet the problems that arise from unemployment and depleted family resources."

And finally, in 1938, Grace Abbott, then director of the Bureau, noted that "programs should be tailored for children and they cannot be merely an adaptation of the program for adults. . .nor should the programs for children be curtailed during periods of depression or emergency expansion of other programs" (10).

Organizationally, the Children's Bureau was initially placed in the U.S. Department of Labor. In 1930, the Preliminary Committee Reports of the White House Conference on Child Health and Protection recommended that the Division of Child Hygiene and Maternity and Infancy of the Children's Bureau be moved to the Public Health Service (10). In 1946, the Children's Bureau was moved from the U.S. Department of Labor to the Federal Security

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Box 19-A—History of the Children's Bureau—Continued

Agency, then responsible for Social Security programs. In 1953, the Family Support Administration was absorbed by the U.S. Department of Health, Education and Welfare, and the Children's Bureau became part of the Social Security Administration. In 1963, the Bureau was moved from the Social Security Administration to the Welfare Administration, and again in 1967, the Bureau was further assigned to Social and Rehabilitation Services. The medical services component, maternal and child health, was subsequently moved to the Public Health Service in the Health Services and Mental Health Administration. The social services component remained in the U.S. Department of Health, Education, and Welfare and then became part of the U.S. Department of Health and Human Services, Office of Human Development Services, Administration for Children, Youth, and Families.

The Children's Bureau exists today. However, its function is much changed from the broad charge given it in 1912. Today, its responsibilities focus primarily on administering child welfare grants. Other child related programs in the U.S. Department of Health and Human Services are now found in the Administration on Children, Youth, and Families, Bureau of Maternal and Child Health, National Institute of Child Health and Human Development and other Institutes within the National Institutes of Health, Centers for Disease Control, and agencies within the Alcohol, Drug Abuse, and Mental Health Administration. No single unit within the U.S. Department of Health and Human Services at this time serves as a central coordinating or clearinghouse for the department's adolescent initiatives.

istration's Bureau of Health Care Delivery and Assistance (17 percent), the National Institutes of Health's National Institute of Allergy and Infectious Diseases (15 percent), the Alcohol, Drug Abuse, and Mental Health Administration's National Institute of Mental Health (12 percent).

In non-DHHS agencies responding to OTA's survey, adolescents tend to receive a larger proportion of appropriated money, although the total amounts are small (see table 19-5). The U.S. Department of Justice, for example, directs approximately 20 percent of its National Institute of Justice funds and all of its Office of Juvenile Justice and Delinquency Prevention funds to adolescents. In addition, the U.S. Department of Agriculture's Extension Service, and the U.S. Department of Education's National Institute on Disability and Rehabilitation Research direct over 20 percent of their funds specifically to adolescents.

A very rough estimate by OTA, based on data able to be provided by the range of U.S. executive branch agencies with a role in adolescent health, is that, in fiscal year 1988, adolescent health initiatives accounted for perhaps 2 percent of the $533 billion in Federal expenditures (102a) for domestic "human resources" or "social welfare" programs.[52]

Most Federal agencies surveyed by OTA do not provide specific set-asides for adolescents. Instead, they often include adolescents as part of a larger, more general, research or service focus. Because adolescents require comprehensive, continuous, developmentally appropriate, labor-intensive interventions, they may not receive the services they need when they are included as part of populations serving children in general or adults.

Federal agency priorities are often determined by authorizing legislation or executive directive. In some cases, the result is that resources available to serve the needs of adolescents are quite limited. Federal agency representatives at OTA's meeting indicated that direction for changing agencies' short- and long-term priorities must come from the President or Congress. To make adolescent health a priority, Federal agency representatives expressed the need for additional appropriated funds or for current funds to shift from other areas and suggested Congress could heighten awareness of adolescents and their health needs through a series of hearings.

Currently, the Federal Government places heavy emphasis on supporting programs and projects related to the consequences of adolescent sexual

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[52] "Human resources" or "social welfare" programs include the budget "functions" of education, training, unemployment, and social services; health; Medicare; income security; social security; and veterans benefits and services (41a,102a). Recent changes in the Federal budget as they pertain to domestic spending, and the potential consequences for adolescent health initiatives, are discussed more fully in *Volume I—Summary and Policy Options* of this Report (44b). The budget share would be higher if the adolescent share of AFDC payments were known.

Table 19-6—Congressional Committees With a Role in Adolescent Health[a]

AP = Handles appropriations
B = Sets funding guidelines
AU = Authorizes major program areas
A = Authorizes specific programs
O = Oversight of programs
T = Jurisdiction over funding sources such as trust funds

Congressional committees and subcommittees[b]	Families	Schools and education	Work, recreation, and fitness	Nutrition	Special groups	Health and related services (delivery and access)	Financial access to health services	Future competitiveness and defense readiness	Other
Senate committees									
Agriculture, Nutrition, and Forestry[c]				AU/O	A/O				
Nutrition and Investigations									
Appropriations[d]	AP/O	AP/O	AP/O	AP/O	AP/O	AP/O	AP/O	AP/O	AP/O
Armed Services[e]						A/O	A/O	A/O	
Banking, Housing, and Urban Affairs[f]	A/O				A/O				
Housing and Urban Affairs									
Budget	O	O	O	O	O	O	O	O	O
Commerce, Science, and Transportation[g]			AU/O						AU/O
Environment and Public Works[h]			A/O					AU/O	
Finance[i]	T/O					T/O	AU/T/O		
Social Security and Family Policy									
Health for Families and the Uninsured									
Governmental Affairs[j]	O	O	O	O	O	O	O	O	AU/O

[a] Except where noted, the congressional committees shown in this table are standing committees. *Standing committees* are committees that are permanent bodies of either the House or the Senate, have responsibility for broad areas of legislation (e.g., agriculture), and are responsible for most of the legislation considered by Congress. The Senate has 16 standing committees, and the House has 22 standing committees. *Select committees* are committees created to study particular problems or concerns (e.g., Select Committee on Children, Youth, and Families). These committees make recommendations but are usually not permitted to report legislation to Congress (the one exception is the Select Intelligence Committee). Joint committees are committees composed of members from both the House and the Senate. The Joint Economic Committee is the only joint committee which has a policy role v. an administrative role, and reports its findings to Congress.

[b] Only subcommittees that deal extensively with legislation related to adolescent health are noted. A *subcommittee* is an offshoot of a standing or joint committee and deals with a particular area covered by the full committee. There are usually a number of subcommittees within a particular committee. Members of the subcommittee are also members of the full committee. Subcommittees hold hearings and amend bills relating to their particular topic area. The amendments must be voted on in the full committee before returning to the House or Senate floor.

[c] The Senate Agriculture, Nutrition, and Forestry Committee authorizes and exercises oversight over numerous programs administered by the U.S. Department of Agriculture, including food and nutrition programs (e.g., the Food Stamp Program, school nutrition programs) and programs related to rural development.

[d] The following subcommittees of the Senate Appropriations Committee deal with programs relevant to adolescent health: Agriculture, Rural Development, and Related Agencies; Commerce, Justice, and State, the Judiciary, and Related Agencies; Defense; Interior and Related Agencies; Labor, Health and Human Services, Education and Related Agencies; and Transportation and Related Agencies.

[e] The Senate Armed Services Committee authorizes and exercises oversight over numerous programs administered by the U.S. Department of Defense, including the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), a civilian health and medical program for retirees and the spouses and dependent children of active duty, retired, and deceased military personnel.

[f] The Senate Banking, Housing, and Urban Affairs Committee authorizes and exercises oversight over programs administered by the U.S. Department of Housing and Urban Development, including public and private housing programs and community development block grants.

[g] The Senate Commerce, Science, and Transportation Committee authorizes and exercises oversight over programs administered by the U.S. Department of Transportation, including programs related to highway and motor vehicle transportation safety.

[h] The Senate Environment and Public Works Committee authorizes and exercises oversight over programs administered by the Environmental Protection Agency that alleviate or reduce noise, water, and air pollution.

[i] The Senate Finance Committee authorizes health programs under the Social Security Act, including Medicaid.

[j] The Senate Governmental Affairs Committee has jurisdiction over programs of the Census Bureau, and over the organization of Congress and the U.S. executive branch.

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Table 19-6—Congressional Committees With a Role in Adolescent Health[a]—Continued

AP = Handles appropriations
B = Sets funding guidelines
AU = Authorizes major program areas
A = Authorizes specific programs
O = Oversight of programs
T = Jurisdiction over funding sources such as trust funds

Congressional committees and subcommittees[b]	Families	Schools and education	Work, recreation, and fitness	Nutrition	Special groups	Health and related services (delivery and access)	Financial access to health services	Future competitiveness and defense readiness	Other
Judiciary[k]					AU/O				AU/O
Labor and Human Resources[l]	AU/O	AU/O	AU/O	AU/O	AU/O	AU/O	AU/O	AU/O	AU/O
Labor									
Education, Arts, and Humanities									
Employment and Productivity									
Disability Policy									
Children, Family, Drugs, Alcoholism									
Select Committee on Indian Affairs					O	O	O		
House committees									
Agriculture[m]				A/O	AU/O				
Conservation, Credit, and Rural Development									
Domestic Marketing, Consumer Relations, and Nutrition									
Appropriations[n]	AP/O	AP/O	AP/O	AP/O	AP/O	AP/O	AP/O	AP/O	AP/O
Armed Services[o]						A/O	A/O	A/O	
Banking, Finance, and Urban Affairs[p]	A/O				A/O				
Housing and Community Development									
Budget	O	O	O	O	O	O	O	O	O

[k] The Senate Judiciary Committee authorizes and exercises oversight over programs administered by the U.S. Department of Justice, including Office of Justice and other programs related to juvenile justice and delinquency prevention.

[l] The Senate Labor and Human Resources Committee authorizes and exercises oversight over a wide range of programs related to health, education, labor, and public welfare. It has jurisdiction over the Public Health Service Act, substance abuse programs, education programs, and numerous other programs related to children and families.

[m] The House Agriculture Committee authorizes and exercises oversight over programs administered by the U.S. Department of Agriculture, including food and nutrition programs (e.g., the Food Stamp Program, school nutrition programs) and programs related to rural development.

[n] The following subcommittees of the House Committee on Appropriations deal with programs relevant to adolescent health: Commerce, Justice, and State, the Judiciary, and Related Agencies; Defense; Interior and Related Agencies; Labor, Health and Human Services, Education, and Related Agencies; Rural Development, Agriculture, and Related Agencies; and VA, HUD, and Independent Agencies.

[o] The House Armed Services Committee authorizes programs administered by the U.S. Department of Defense, including CHAMPUS (see Senate Armed Services Committee above).

[p] The House Banking, Finance, and Urban Affairs Committee authorizes and exercises oversight over programs administered by the U.S. Department of Housing and Urban Development, including housing and community development programs.

Table 19-6—Congressional Committees With a Role in Adolescent Health[a]—Continued

AP = Handles appropriations
B = Sets funding guidelines
AU = Authorizes major program areas
A = Authorizes specific programs
O = Oversight of programs
T = Jurisdiction over funding sources such as trust funds

Congressional committees and subcommittees[b]	Families	Schools and education	Work, recreation, and fitness	Nutrition	Special groups	Health and related services (delivery and access)	Financial access to health services	Future competitiveness and defense readiness	Other
Education and Labor[q] Elementary, Secondary, and Vocational Education Health and Safety Employment Opportunities Select Education	AU/O	AU/O	AU/O	A/O	A/O				AU/O
Energy and Commerce[r] Health and the Environment	AU/O		AU/O	AU/O	AU/O	AU/O	A/O		A/O
Government Operations[s]	O	O	O	O	O	O	O	O	AU/O
Interior and Insular Affairs[t]	AU/O		AU/O		AU/O	AU/O	AU/O		
Judiciary[u]	AU/O				AU/O				AU/O
Post Office and Civil Service[v]	A/O				A/O	A/O	A/O		A/O
Science, Space, and Technology[w]		A/O						AU/O	AU/O
Ways and Means[x] Health Human Resources	AU/O			A/O		AU/O	AU/O		
Select Committee on Children, Youth, and Families	O	O	O	O	O	O	O	O	O
Select Committee on Hunger	O	O		O	O	O	O		
Select Committee on Narcotics Abuse and Control[y]	O	O	O			O	O		O
Joint committees									
Joint Economic Committee Economic Resources and Competitiveness Education and Health		O				O		O	O

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[q] The House Education and Labor Committee authorizes and exercises oversight over a wide range of programs related to education, labor standards, human resources programs for the elimination of poverty and the care and treatment of children (e.g., Head Start, community services block grants, juvenile justice and delinquency prevention, and programs for runaway youths), and job training.

[r] The House Energy and Commerce Committee authorizes and exercises oversight over a wide range of programs related to health and the environment. It has jurisdiction over the Public Health Service Act and biomedical programs and health protection in general (including Medicaid and national health insurance). It also has jurisdiction over the Clean Air Act and the Safe Drinking Water Act.

[s] The House Government Operations Committee has oversight responsibilities related to the organization and reorganization of the U.S. executive branch.

[t] The House Interior and Insular Affairs Committee authorizes and exercises oversight over programs administered by the U.S. Department of the Interior, including programs that deal with national parks and several programs that affect Native Americans.

[u] This House Judiciary Committee authorizes and exercises oversight over programs administered by the U.S. Department of Justice, including Office of Justice and other programs related to juvenile justice and delinquency prevention.

[v] The House Post Office and Civil Service Committee has jurisdiction over programs of the Census Bureau and authorizes programs that deal with health and related services for Federal employees and their families.

[w] The House Science, Space, and Technology Committee authorizes research and development in science and technology.

[x] The House Ways and Means Committee authorizes and exercises oversight over numerous programs of the Social Security Act, including AFDC.

[y] The House Select Committee on Narcotics Abuse and Control investigates issues relating to substance abuse and the criminal justice system.

SOURCE: Office of Technology Assessment, based on material from U.S. Congress, Library of Congress, *Congressional Yellow Book* 16(3) (Washington, DC: Monitor Publishing Co., Fall 1990).

intercourse, especially focusing on AIDS and HIV infection and on adolescents' use of illicit drugs. The Division of Adolescent and School Health, for example, spends most of its $33 million on HIV education. The National Institute of Allergy and Infectious Diseases, which spends about $98 million on adolescents, is concentrating primarily on research related to vaccine development and therapeutic approaches for sexually transmitted diseases and AIDS.

With the Federal Government's heavy emphasis on efforts related to adolescent sexual activity and drug use, other more prevalent health problems, such as unintentional injuries, the greatest killer of adolescents, receive less attention.[53] The Centers for Disease Control's Division of Injury Control, for example, targets just over $3 million on injury control for adolescents, less than a tenth of the funds that the Centers for Disease Control spends on HIV education. Adolescents' own subjective distresses are also little attended to.

Perhaps one reason health issues, other than those related to sexual intercourse and substance use, receive relatively little Federal funding is the current lack of data on adolescent health defined broadly and the limited availability and dissemination of data that are both relevant and timely.[54]

The Office of Treatment Improvement, the U.S. Departments of Education and Justice, the Health Resources and Services Administration, and the Family Support Administration award most, if not all, of their physical and mental health education, prevention, and social service activities funds through block grants. Because the Federal Government does not determine the mix of services that States provide under block grant programs (except within broad guidelines), the Federal Government's ability to affect the health of adolescents is limited. States receiving block grant awards, even maternal and child health block grants, do not necessarily choose to allocate funds to adolescents and their health problems. The Federal Government could earmark funds to adolescents within block grants, but the procedure has the disadvantage of limiting States' ability to control services.

The other primary way the Federal Government provides funding related to adolescent health also presents a dilemma. Funds are often limited to research or demonstration projects awarded on a competitive basis.[55] As with block grant programs, it is often difficult to know whether those adolescents most in need of will be reached by the demonstration projects that survive the Federal grantmaking process. However, there is reason to believe that the needs of adolescents may not be adequately met by such a relatively passive approach, for several reasons. The overall grant amounts are generally small; adolescents are not specifically mentioned in many authorizing legislation or grant announcements; and the most adept at writing grant proposals, rather than those most in need, are most likely to receive funding.

This limited Federal role is a consonant with the overall current Federal approach to domestic issues, which is far less active than it has been at other times.[56] Further, with limited direct Federal involvement in social programs, a competitive approach to grantmaking helps to ensure that Federal dollars are well spent. Given the critical needs of adolescents, however, it is not clear that such an approach is sufficient.

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[53] See ch. 5, "Accidental Injuries: Prevention and Services," in Vol. II.

[54] *Volume I—Summary and Policy Options* includes discussions of crosscutting issues in the definition of adolescent health (box A) and in the collection and dissemination of data on adolescent health and health services (app. C) (44b). Further, data collection issues related to specific adolescent health concerns (e.g., accidental injuries, chronic physical illness, mental health, delinquency, homelessness) are discussed in the chapters in Volume II of this Report, to be released later in 1991.

[55] Recent examples include:

- Grants authorized under the Education of the Handicapped Act Amendments of 1990 (Public Law 101-476) to institutions of higher education and local educational agencies (acting in collaboration with mental health entities) to improve services to students who are in special education programs as a consequence of having a serious emotional disturbance; this program is designed to address the longstanding need of such students for the mental health services that are not explicitly mandated by the original Education for All Handicapped Children Act (Public Law 94-142). For further discussion, see ch. 11, "Mental Health Services: Prevention and Services," in Vol. II.
- Grants authorized by the National and Community Service Act of 1990 to States or local applicants for: the creation or expansion of service opportunities for students (Title I, Subtitle B); and the creation or expansion of full-time or summer youth service corps programs focusing on conservation and human resources (Title I, Subtitle C), among other provisions. These programs are designed to fill several purposes, including: build self-esteem; teach teamwork, decisionmaking, and problemsolving; and tap youth as a resource for community service. For further discussion, see ch. 4, "Schools and Discretionary Time," in Vol. II.
- Grants authorized by Title V of the Stewart B. McKinney Homeless Assistance Amendments Act of 1990 (Public Law 101-645) to support demonstration projects regarding outreach and comprehensive primary health services for homeless children. For further discussion, see ch. 14, "Homelessness: Prevention and Services," in Vol. II.

Certain Federal policies specific to adolescents have the effect of limiting the types of services adolescents receive. For example, the Government's emphasis on abstinence from sexual intercourse provides important limitations to the type of services that adolescents engaging in these activities can receive (67). If pregnancy occurs and an abortion is desired, no Title X or Title XX funds can be used to provide abortions, education and counseling for abortion services, or abortion referral (54 FR 35440) (19,94).

Given Federal agencies' limited ability to fund activities and the potential for duplication of or gaps in efforts, many Federal representatives expressed their desire to collaborate and coordinate more frequently with other agencies serving adolescents. Although there is some coordination ongoing within and between Federal agencies through interagency agreements, particularly in the areas of drug education and juvenile justice issues, many representatives were unaware of other Federal agencies' projects and programs. Barriers to collaboration include constraints inherent in congressional enabling legislation, the lack of a consistent definition of adolescence, agencies' disagreement as to what is needed to improve the health of adolescents, lack of incentives to cooperate, and lack of leadership on adolescent issues.

Currently, there are no incentives or rewards for Federal agencies to collaborate, and no mechanism has been established through which information is shared. There are several ways in which greater collaboration could be encouraged. First, Congress could establish a reward structure to encourage collaboration or could set up a separate fund for collaborative efforts. Additionally, an individual in each Federal agency could be responsible for coordinating adolescent issues within and between agencies. In fact, the idea of having an adolescent health coordinator is not a new one. Some State governments recognize the need to have a health coordinator for adolescents. The Bureau of Maternal and Child Health within the Health Resources and Services Administration supports coordination among the various State adolescent health care coordinators, although it does not directly support the coordinating function in any one State. However, no such level of coordination exists between Federal agencies. Instituting one Federal adolescent coordinator responsible for coordination across all agencies could improve adolescent services and programs as well as create a strong national advocate for addressing the health needs of adolescents.

Mere coordination may not be sufficient. In fact, several observers suggested that a new Federal agency may be needed to organize the resources necessary to improve the health of adolescents.

Clearly, the Federal Government has an important role in improving the health of adolescents. Although funding research and demonstration projects is an essential component of that role, the coordination of Federal efforts is and can be a more important component of the Federal Government's responsibility to approximately 12 percent of the Nation's population. Specific policy options on the Federal role in adolescent health—across a broad range of issues—can be found in Volume I of OTA's *Adolescent Health* Report.

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[56] As summarized by Brindis and Lee in their discussion of public policy issues affecting the health care delivery system for adolescents, ". . .the United States evolved from a pattern of *dual federalism*, with a limited role in domestic affairs for the federal government, to *cooperative federalism*, with a strong federal role in the 1930s. . .The term *creative federalism* was applied to policies developed during [the early and middle 1960s] that extended the traditional federal-state relationship to include direct federal support for local governments (cities and counties), nonprofit organizations, and private business and corporations to carry out health, education, training, social services, and community development programs. During the 1970s, President Richard M. Nixon coined the term *new federalism* to describe his efforts to move away from the categorical programs of the Johnson years. . .President Reagan extended the idea in the 1980s to limit further the role of government, transferring authority and responsibility to the States, with a reduction in federal funding. . ." *(italics added)* (11a). For further discussion, see *Volume I—Summary and Policy Options* (44b).

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APPENDIXES

Appendix A

GLOSSARY OF ABBREVIATIONS AND TERMS

Abbreviations

AAP—American Academy of Pediatrics
ACOG—American College of Obstetrics and Gynecology
ADAMHA—Alcohol, Drug Abuse, and Mental Health Administration (Public Health Service)
AFDC—Aid to Families With Dependent Children
AIDS—acquired immunodeficiency syndrome
AMA—American Medical Association
CASSP—Child and Adolescent Service System Program (National Institute of Mental Health)
CDC—Centers for Disease Control (Public Health Service)
CFR—Code of Federal Regulations
CHAMPUS—Civilian Health and Medical Program of the Uniformed Services (U.S. Department of Defense)
CHC—community health center
CPO—Center for Population Options
DHHS—U.S. Department of Health and Human Services
DSM-III—*Diagnostic and Statistical Manual*, 3rd edition
EPSDT—Early and Periodic Screening, Diagnosis, and Treatment program (Medicaid)
ERISA—Employee Retirement and Income Security Act (Public Law 92-104)
FR—Federal Register
FSA—Family Support Administration (U.S. Department of Health and Human Services)
HCFA—Health Care Financing Administration (U.S. Department of Health and Human Services)
Hispanic HANES—Hispanic Health and Nutrition Examination Survey (National Center for Health Statistics)
HIV—human immunodeficiency virus
HMO—health maintenance organization
HRSA—Health Resources and Services Administration (Public Health Service)
IHS—Indian Health Service (Public Health Service)
IQ—intelligence quotient
JOBS—Job Opportunity and Basic Skills training program (Family Support Administration)
NAMCS—National Ambulatory Medical Care Survey (National Center for Health Statistics)
NCHS—National Center for Health Statistics (Centers for Disease Control)
NHANES—National Health and Nutrition Examination Survey (National Center for Health Statistics)
NHIS—National Health Interview Survey (National Center for Health Statistics)
NIH—National Institutes of Health (Public Health Service)
NIMH—National Institute of Mental Health (Alcohol, Drug Abuse, and Mental Health Administration)
NSFG—National Survey of Family Growth (National Center for Health Statistics)
OASH—Office of the Assistant Secretary for Health (U.S. Department of Health and Human Services)
OB/GYN—obstetrics/gynecology
OBRA-81—Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35)
OBRA-89—Omnibus Budget Reconciliation Act of 1989 (Public Law 101-239)
OBRA-90—Omnibus Budget Reconciliation Act of 1990 (Public Law 101-508)
OHDS—Office of Human Development Services (U.S. Department of Health and Human Services)
OJJDP—Office of Juvenile Justice and Delinquency Prevention (U.S. Department of Justice)
OTA—Office of Technology Assessment (U.S. Congress)
PHS—U.S. Public Health Service (U.S. Department of Health and Human Services)
PPO—preferred provider organization
SAM—The Society for Adolescent Medicine
SLHC—school-linked health center
SPRANS—special projects of regional and national significance
SSI—Supplemental Security Income program (U.S. Department of Health and Human Services)
STD—sexually transmitted disease
VISTA—Volunteers in Service to America (ACTION)
WIC—Special Supplemental Food Program for Women, Infants, and Children (U.S. Department of Agriculture)

Terms

Access: Potential and actual entry of a population into the health care delivery system. Elements of access include availability, affordability, and approachability.

Acute condition: A problem or disease of limited duration, as opposed to chronic. According to the DHHS National Center for Health Statistics, a condition is considered acute if: 1) it was first noticed no longer than 3 months before the reference date of the interview and 2) it is not one of the conditions considered *chronic* regardless of the time of onset. However, any acute condition is not associated with either at least one doctor visit or at least 1 day of restricted activity is considered to be of minor consequence and is excluded from the final data produced by the DHHS National Center for Health Statistics' *National Health Interview Survey.*

Adolescence: Definitions of adolescence vary, and many observers agree that a definition based on age alone is not sufficient. Adolescence typically takes place during the second decade of life, and is initiated by *puberty*, although physical and other changes occur (i.e., in height, weight, head size, facial structure, facial expression, and cognitive abilities). As used by OTA, adolescence most often refers to the period of life from ages 10 through 18. See *early adolescence, middle adolescence, late adolescence, younger adolescents, older adolescents.*

Adolescent health: Narrow definitions of adolescent health might be the absence of physical disease and disability and the absence of engagement in health-compromising behaviors that lead to the so-called *new morbidities.* A broader definition would also include positive components of health (e.g., social competence); and health and well-being from the perspective of adolescents themselves (e.g., perceived quality of life). A fully realized view of adolescent health would also consider the impact of social (e.g., families, schools, communities, policies) and physical (e.g., fluoridation, automobile and highway design and construction) influences on health and would be sensitive to developmental changes that occur during adolescence. See also *health.*

Adolescent medicine: A certified medical subspecialty of pediatrics, focusing on the care of adolescents. See *pediatrician.*

Advocacy: Refers to support, coordination and linkage to experts, individuals, groups, and institutions who may help adolescents. May be provided by parents or others known to an adolescents.

Age of majority: The age at which by law a person is entitled to the management of his or her own affairs and to the enjoyment of civic rights. Currently, the age of majority is set at age 18 in every State but Alaska, Nebraska, and Wyoming, where the age is 19.

AIDS (acquired immunodeficiency syndrome): A disease caused by *human immunodeficiency virus (HIV)* and characterized by a deficiency of the immune system. The primary defect in AIDS is an acquired, persistent, quantitative functional depression within the T4 subset of lymphocytes. This depression often leads to infections caused by micro-organisms that usually do not produce infections in individuals with normal immunity. HIV infection can be transmitted from one infected individual to another by means that include the sharing of a contaminated intravenous needle and engaging in *unprotected sexual intercourse* (i.e., intercourse without the use of condoms).

Aid to Families With Dependent Children (AFDC) program: A program, established by the Social Security Act of 1935, providing cash payments to needy children (and their caretakers) who lack support because at least one parent is dead, disabled, continually absent from the home, or unemployed. Eligible families must meet income and resource criteria specified by the State.

Alcohol abuse: See *substance abuse.*

Alcohol, drug abuse, and mental health (ADM) block grant: The major Federal program providing funds to States for outpatient alcohol, drug abuse, and mental health treatment programs. (Funds are not allowed to be used for *inpatient* services.) States receive a share of the ADM block grant appropriation through a formula based in part on the size of the State population (Subpart 1, part B of title XIX of the Public Health Service Act). The ADM block grant is administered by the Office of Treatment Improvement in the Alcohol, Drug Abuse, and Mental Health Administration in DHHS.

Ambulatory care: Health care services provided to patients who are not inpatients of hospitals or other residential facilities (e.g., residential treatment centers, nursing homes). May include care provided in a hospital on an *outpatient* basis. But see *National Ambulatory Medical Care Survey, National Health Interview Survey, office visit,* and *physician contact.*

Anticipatory guidance: The provision of health education, information, or counseling about topics important to health, optimally before problems have arisen.

Block grants: Sums of Federal funds allotted to State agencies (e.g., education, health) which may be passed onto local agencies. States determine the mix of services provided and the population served and are accountable to the Federal Government only to the extent that funds are spent in accordance with program requirements. Sometimes, however, set-asides are required for specific population groups.

Case law: The body of law created by judicial opinions rendered in legal cases in contrast to statutory law generated by legislatures.

Chronic condition: A problem or disease that is lingering and lasting, as opposed to acute. For purposes of DHHS' *National Health Interview Survey*, a condition is considered "chronic" if: 1) the respondent indicates it was first noticed more than 3 months before the reference date of the interview and it exists at the time of the interview, or 2) it is a type of condition that ordinarily has a duration of more than 3 months. Examples of conditions that are considered chronic regardless of their time of onset are diabetes, heart conditions, emphysema, and arthritis.

Civilian Health and Medical Program of the Uniformed Services (CHAMPUS): A health insurance program, administered by the U.S. Department of Defense, that provides health benefits to military dependents and retirees who are unable to receive services through uniformed service medical treatment facilities.

Civilian noninstitutional population: The civilian population not residing in institutions. Institutions include correctional institutions, detention homes, and training schools for juvenile offenders, homes for dependent and neglected children, homes and schools for the mentally or physically handicapped, and homes for unwed mothers. This population is the denominator in rates calculated for the *National Ambulatory Medical Care Survey*, the *National Health and Nutrition Examination Survey*, and the *National Health Interview Survey*.

Coinsurance payment: A specified percentage, usually 20 percent, that a person with health insurance must pay for each covered service up to an annual limit (e.g., $1,500) after which the plan pays 100 percent of covered benefits. Compare *deductible*.

Common law: As distinguished from statutory law created by a legislature, the body of principles and rules of action which derive their authority solely from long-standing usages and customs (in particular, Anglo-American usages and customs) or from the judgments and decrees of the courts recognizing, affirming, and enforcing such usages and customs.

Common law rule: A rule grounded in common law (see above) rather than in statutory law.

Community health center (CHC): An organization that provides primary health care and other health related services to individuals in the local community. As of 1989, there were about 1,200 community health centers providing services at more than 2,000 sites throughout the country. Roughly half of these centers were receiving Federal grants under Section 330 of the Public Health Service Act, which authorizes grants to public and private nonprofit organizations that provide primary health care to populations or areas that are "medically underserved."

Competence (to make health care decisions): Having sufficient knowledge, judgment, or skill to make health care decisions. The legal concept of competency is central to existing laws governing health care decisionmaking with respect to minors, and the *parental consent requirement* is partially an outgrowth of the presumption that minors are incompetent to make health care decisions.

Comprehensive centers for adolescents: School-linked or community-based centers provide *comprehensive services for adolescents*.

Comprehensive services for adolescents: The elements of comprehensive health and related services for adolescents are not entirely agreed upon. They include, at a minimum, care for acute physical illnesses, general medical examinations in preparation for involvement in athletics, mental health counseling, laboratory tests, *reproductive health care*, *family counseling*, prescriptions, *advocacy*, and coordination of care; the more comprehensive may include educational services, vocational services, legal assistance, recreational opportunities, child care services and parenting education for adolescent parents. Not all services are available at all centers, but a well-functioning comprehensive services center would provide for the coordinated delivery of care both within the center and between the center and outside agencies and providers.

Confidentiality (of the physician/patient relationship): The state or quality of being confidential, that is intended to be held in confidence or kept secret. Courts and legislatures have established a physician-patient privilege to protect the confidentiality of communications between physicians and their patients and have established similar privileges to ensure the confidentiality of communications between other types of health care providers and their patients or clients. By and large, the confidentiality of the relationship between health service providers and minors and the disclosure of confidential information by health service providers to the parents of minors or other third parties are not addressed in case or statutory law.

Consent: See *informed consent*, *parental consent requirement*.

Constitutional law: The branch of law that involves the U.S. Constitution.

Contraception: The prevention of conception or impregnation by any variety of means, including periodic abstinence (rhythm method); control of ejaculation (coitus interrupts); the use of spermicidal chemicals in jellies or creams; mechanical barriers (e.g., condoms, caps, or diaphragms); prevention of implantation (e.g., intrauterine device); the use of synthetic hormones to control the female reproductive cycle (e.g., the oral contraceptive pill); and sterilization of the male or female partner.

Contract: An agreement, express or implied, between two or more persons which creates an obligation to do or not to do a particular thing. Its essentials are competent parties, subject matter, legal consideration, mutuality of agreement, and mutuality of obligation. The relationship between a physician and an adult patient is usually considered a contractual relationship.

Contract law: Law pertaining to contracts (see above).

Conventional health insurance plan: A traditional indemnity or fee-for-service health insurance plan that typically reimburses the health provider on a "reasonable and customary" basis or as billed. Distinguished from *health maintenance organizations (HMOs)* and *preferred provider organization (PPOs).* Compare *managed fee-for-service plan.*

Copayment: See *coinsurance payment.*

Covariation: The tendency of health problems to occur in the same individual at approximately the same time. The problems may have a single common cause, or one problem may be the cause of another.

Culturally competent: A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations. A culturally competent system of care acknowledges and incorporates—at all levels—the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally unique needs. See *culture.*

Culture: Implies the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group.

Current Population Survey (CPS): A household sample survey of the *civilian noninstitutionalized population* that provide estimates of employment, unemployment, and other characteristics of the general labor force, the population as a whole, and various other subgroups of the population. The survey is conducted monthly by the Bureau of the Census within the U.S. Department of Commerce. Annual data on the number of people living in poverty and their characteristics, based on income during the previous year and families' status as of March of the current year, are obtained in the March supplement to the Current Population Survey, which surveys a sample of households from the most recent decennial census.

Deductible: A specific dollar amount, usually about $400 per family, that must be paid before a health insurance plan begins paying benefits.

Demonstration project: An intervention that is typically in an experimental (unproven) stage of effectiveness and is supported for a limited period with an evaluation component.

Diagnosable mental disorders: Disorders included in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, 3rd ed., revised.

Discretionary spending programs (in the Federal budget): Those spending programs subject to the annual appropriations process. Compare *entitlement programs.*

Early adolescence: A period encompassing the profound physical and social changes that occur with *puberty*, as maturation begins and social interactions become increasingly focused on sex (e.g., on members of the opposite sex). Typically takes place from ages 10 through 14. Compare *middle adolescence, late adolescence, younger adolescents, older adolescents.*

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program: A State and federally funded, State-administered program under Medicaid that is intended to provide preventive screening exams and followup services for illnesses, abnormalities, and treatable conditions to Medicaid-eligible children under age 21. The EPSDT benefit was enacted in 1967; with changes introduced in 1989, EPSDT offers the most comprehensive child and adolescent preventive care package currently available in any private or public financing plan. As such, it is potentially the most important primary care benefit available to adolescents covered by Medicaid.

Emancipated minor: A minor who has been legally freed from the control and authority of his or her parents. Under the common law doctrine of emancipation, emancipation may be expressed, as by voluntary agreement of the parent and child, or implied from such acts and conduct as import consent (e.g., a minor's marriage or establishment of a home away from that of his or her parents); it may be complete or partial; and it may or may not result in a minor's having the right to consent to health services. About half the States have enacted statutes that allow for court-ordered emancipation. In some States, these statutes explicitly state that emancipation removes the disabilities of minority, including the requirement of parental consent to health services.

Employer mandate: A requirement imposed by the Federal Government on the States that employers offer group health insurance policies and pay a significant amount of the premiums for all employees who work more than a specified number of hours per week.

Employment-based group health plans: A *group health plan* that is offered to employees by an employer. The terms private health insurance, private health plans, and group health plans are often used interchangeably in this volume to refer to employment-based group health plans.

Entitlement programs: Programs that provide benefits paid out automatically to all who qualify unless there is a change in underlying law (examples include Federal employee retirement benefits, Medicare, *Med-*

icaid, unemployment compensation, *Aid to Families With Dependent Children*).

Ethnicity: A term used to indicate national origin (e.g., Hispanic). Most census and health status information is available for individuals of *Hispanic* origin. Compare *race*.

Family autonomy: Noninterference by the state in the right of families to make important decisions concerning family life and family members. A tradition of family autonomy is deeply embedded in Anglo-American law and can be traced back to Roman law, the Judeo-Christian tradition, and Anglo-Saxon customary law. Family autonomy is often, but not always, equated with parental authority.

Family composition: See *family structure*.

Family counseling: Counseling provided to an entire family rather than solely to an individual.

Family planning: A range of services intended to help individuals plan when to have children, from counseling concerning the advisability of initiating sexual intercourse to the provision of contraceptive methods. Services may be provided in freestanding family planning clinics or in more general health services settings. See *contraception*, *Title X of the Public Health Service Act*.

Family structure: Used to describe the relationship between dependent children and the adult head(s) of household with whom they reside. In this report, typically includes: a family consisting of children and a single parent (a single parent family); children living with their biological parents (sometimes called an "intact" family); dependent children living with a biological parent and a stepparent (stepfamily or blended family); and dependent children not living with a parent.

Federal poverty level: The official U.S. Government definition of poverty based on cash income levels for families of different sizes. Responsibility for changing poverty concepts and definitions rests with the Office of Management and Budget.

Fee-for-service: See *conventional health insurance plan*.

Financial access (to health services): In this Report, used to refer to aspects of access that have to do with health insurance coverage and ability to pay for services. Compare *legal access*.

Freestanding (comprehensive) services centers (for adolescents): Those *comprehensive services centers* not located within a school, *health maintenance organization*, hospital, or other facility.

Group health plan: A health insurance plan that is obtained, not on an individual or family basis, but through an employment or other membership contract. Also see *employment-based group health plan*. The terms private health insurance, private health plans, and group health plans are often used interchangeably in this volume to refer to employment-based group plans.

Health: Most broadly, a state of optimal physical, mental, and social well-being, and not merely the absence of disease and infirmity. See *adolescent health*.

Health care provider: Any of the broad range of disciplines that specialize in providing health care services. Includes, but is not necessarily limited to, health educators, nurses, nurse-midwives, nurse-practitioners, psychiatric nurses, clinical psychologists, clinical social workers, and physicians.

Health education: Activities aimed at influencing behavior in such a way as it is hoped will assist in the promotion of health and the prevention of disease.

Health maintenance organization (HMO): An organization that, in return for a prospective per capita (capitation) payments, acts as both insurer and provider of comprehensive but specified health care services to a voluntarily enrolled population. Prepaid group practices and individual practice associations are types of HMOs.

Health outcome: A measure of the effectiveness of preventive or treatment health services, typically in terms of patient health status, but sometimes in terms of patient satisfaction. Attributing changes in outcomes to health services requires distinguishing the effects of the many other factors that influence patients' health and satisfaction.

Health promotion: Most broadly, a philosophy of health or a set of activities that takes as its aim the promotion of health, not just the prevention of disease. Sometimes narrowly defined as the set of prevention efforts aimed at changing individual behavior: Compare *health education*, *health protection*, and *preventive health services*.

Health protection: Strategies for health promotion and disease prevention related to environmental or regulatory measures that confer protection on large population groups.

Health services system: Traditionally, the aggregation of diagnostic and treatment services delivered by health care professionals, including physicians, physician assistants, nurses, nurse-practitioners, psychologists, and health educators.

Hispanics: Persons who identify themselves as of Hispanic origin, or, less typically, individuals with Hispanic surnames identified by others (e.g., health care providers identifying patients in surveys) as of Hispanic origin. Hispanics can be those whose families have emigrated directly from Spain, or from Cuba, Central or South America. Persons of Hispanic origin can be of any *race* (white, black, American Indian); most have been found to be white. See *ethnicity*.

Human immunodeficiency virus (HIV): The virus that causes *AIDS*.

Human resources programs: In the U.S. Federal budget, includes the following broad categories of Federal expenditures: education, training, employment, and social services; health; Medicare; income security; social security; and veterans benefits and services. Human resources programs are referred to by some as "social welfare programs." Does not include Federal expenditures related to: national defense; physical resources (i.e., energy; natural resources and environment; commerce and housing credit; transportation; and community and regional development); net interest; and "other functions" (i.e., international affairs; general science, space and technology; agriculture; administration of justice; general government; and allowances).

Indian: In this Report, refers to Native Americans in the continental United States, and Indians, Aleuts, and Eskimos in Alaska.

Informed consent: A person's agreement to allow something to happen (e.g., a medical procedure) that is based on a full disclosure of facts needed to make the decision intelligently. Informed consent is also the name for a general principle of law that a physician has a duty to disclose information about the risks of a proposed treatment to a patient so that the patient may intelligently exercise his or her judgment about whether to undergo that treatment.

Informed consent doctrine: A legal doctrine, developed in judicial opinions and codified by legislation, that imposes a legal duty on physicians to give their adult patients information necessary for the patients to make an informed and voluntary choice regarding proposed medical treatment or surgery; a physician's failure to obtain a patient's informed consent may give rise to civil liability. Although the doctrine of informed consent is based on the premise that every person has a right to determine what is done to his or her body, the focus of the doctrine as it has been articulated and applied is on the duty of health professionals to disclose information to patients rather than on the patients' understanding of the information.

Inpatient care: Care that includes an overnight stay in a medical facility.

Internist: A physician who specializes in the diagnosis and medical, as opposed to surgical and obstetrical, treatment of diseases of adults.

Late adolescence: Occurs for those individuals, typically ages 18 to the mid-20s, who, because of educational goals and other social factors, delay their entry into adult roles. Compare *early adolescence, middle adolescence, younger adolescents,* and *older adolescents.*

Legal access (to health services): In this Report, used to refer to aspects of access that have to do with *consent* and *confidentiality.* Compare *financial access.*

Managed fee-for-service plan: A *conventional health insurance plan* which requires patients to obtain prior approval before admission to a hospital and prospective utilization review.

Managed health care: Care provided to enrollees in *managed for-fee service plans, health maintenance organizations (HMOs)* and *preferred provider organizations (PPOs).* Patients in managed health care plans do not have open access to physicians or hospitals and usually must obtain prior approval before admission to a hospital. HMOs and PPOs may also require that the health provider's treatment plan be reviewed to ensure that it is necessary. Patients who do not follow the HMO or PPO guidelines may face larger out-of-pocket costs or be denied payment altogether. Some managed health care plans contain "individual benefits management" programs that allow payment for otherwise uncovered benefits (e.g., home- and community-based services) in order to avoid the utilization of more costly covered services.

Maternal and child health block grants: Under the authority of Title V of the Social Security Act, funds made available to States for the purpose of assuring "access to quality maternal and child health services, especially for those with low incomes and living in areas with limited availability of health services." Distributed and overseen by the Bureau of Maternal and Child Health in DHHS' Health Resources and Services Administration.

Maternity care: Medical services provided from conception, through labor and delivery, and during the postpartum period (through the sixth week after birth).

Medicaid: A federally aided, State-administered program that provides medical assistance for low-income people meeting specific income and family structure requirements.

Medically needy Medicaid recipients: People who receive Medicaid under State "medically needy" programs. States have the option to offer Medicaid to medically needy people who would be categorically eligible for Medicaid but whose income and resources lie above the standards for *Aid to Families With Dependent Children,* (AFDC). Each State sets its own medically needy resource and income standards up to 133 percent of State AFDC income standards.

Medium and large firms: Firms with at least 100 or 250 employees, depending on the industry.

Mental disorders: See *diagnosable mental disorders.*

Mental health problems: See *diagnosable mental disorders,* and *subjective distress.*

Mental health services: Care for the treatment of *mental health problems, third-party payment* for which is usually limited to *diagnosable mental disorders,* and not available for *subjective distress* without an accompanying diagnosable mental disorder.

Middle adolescence: Typically, a time of increasing independence. Generally takes place during the period from ages 15 through 17. For those adolescents who do not go on to (and remain in) college, age 17 or completion of high school marks the end of adolescence, in social terms. Compare *early adolescence*, *late adolescence*, *younger adolescents*, and *older adolescents*.

Minor: A person who has not reached the *age of majority*, either age 18 or 19, depending on the State. Currently, the age of majority is set at age 18 in every State but Alaska, Nebraska, and Wyoming, where the age is 19.

Morbidity: The condition of being diseased or otherwise afflicted with an unhealthful condition. See also *new morbidities*.

National Ambulatory Medical Care Survey (NAMCS): A continuing national probability sample of ambulatory medical encounters. The survey covers physician-patient encounters in the offices of nonfederally employed physicians classified by the American Medical Association or American Osteopathic Association as "office-based, patient care" physicians. It excludes visits to hospital-based physicians, visits to specialists in anesthesiology, pathology, and radiology. It also excludes telephone contacts and non*office visits*. NAMCS is conducted by the National Center for Health Statistics in DHHS.

National Health and Nutrition Examination Survey (NHANES): A survey in which data on the status of the population are obtained by means of direct physical examinations, clinical and laboratory tests, and related measurement procedures. NHANES is the successor to the National Health Examination Survey, which was conducted from 1966 to 1970, and which oversampled adolescents. NHANES I was conducted from 1971 through 1974, NHANES II, from 1976 through 1980, and NHANES III is expected to completed in 1994. NHANES is conducted by the National Center for Health Statistics in DHHS.

National Health Interview Survey (NHIS): A continuing nationwide sample survey in which personal household interviews are used to obtain information on personal and demographic characteristics, illnesses, injuries, impairments, chronic conditions, utilization of health resources, and other health topics. For individuals under age 17, information is collected from a proxy respondent, typically a parent or guardian. NHIS is conducted by the National Center for Health Statistics in DHHS.

National Survey of Family Growth (NSFG): A five-stage area probability sample of civilian noninstitutionalized women ages 15 to 44 and living in the United States. NSFG is conducted by the National Center for Health Statistics in DHHS.

Native American: Typically used to refer to American *Indians* or Alaska Natives, but may also refer to Native Hawaiians.

Near-poor: A term defined in relation to the *Federal poverty level*, a cash income level which varies with family size and the age of the family members. In this Report, near-poor families are families with incomes from 100 percent to 149 percent of the Federal poverty level. The Federal poverty level for a family of three was $10,560 in January 1990.

New morbidities: Illnesses and conditions caused by social and behavioral (rather than organismic) factors (e.g., outcomes of sex, drugs, and violence).

Nonphysician providers: Health care providers other than physicians. They include nurse practitioners, psychologists, clinical social workers, clinical nurse midwives, and drug addiction counselors.

Office visit: For purposes of the National Center for Health Statistics' *National Ambulatory Medical Care Survey*, a physician's office is defined "premises identified by physicians as locations for their *ambulatory* practices, customarily including consultation, examination, or treatment spaces the patients associate with a particular physician." Excludes hospital-based outpatient departments; family planning clinics; government-operated clinics for *sexually transmitted diseases* and maternal and child health; and hospital emergency facilities.

Older adolescents: As defined in most DHHS National Center for Health Statistics data analyses, adolescents ages 15 to 19.

"One-stop" shopping: A setting for health care services that delivers an entire set of *comprehensive health* (and, often, *related*) *services*. Currently an ideal rather than an actuality.

Out-of-pocket expense: Personal expenditures for the portion of health care services not covered by *third-party payment*.

Outpatient care: Care that is provided in a hospital and does not include an overnight hospital stay. Sometimes (as in mental health services) used to refer to all *ambulatory care*.

Parens patriae: Literally "parent of the country," refers traditionally to the role of the state as sovereign and guardian of persons under legal disability (e.g., minors, adults who have been declared legally incompetent).

Parental authority: The deference of the state to the right of parents to make decisions about childrearing. Under common law, minor children were in effect the chattels or property of their parent, who had virtually the unfettered right to rear them as they saw fit. Over time, minor children increasingly have been recognized as having independent rights, yet they are still largely subject to the authority of their parents. In a line of decisions over 50 years, the U.S. Supreme Court has held that parents have a Federal constitutional right to direct the upbringing of their children free from state intervention in the absence of a constitutionally acceptable justification for such intervention. In more recent decisions, however, the Supreme Court has begun to confront conflicts between a parent's asserted right to direct a minor child's upbringing and the minor's assertion of his or her own independent rights and has issued several decisions involving actual or potential parent-child conflicts with respect to the access of minors to contraceptives and abortions and the civil commitment of minors.

Parental consent requirement (applicable to health care of minors): As used in this Report, a legal requirement, grounded in common law, that a parent or other guardian of a minor child must give prior consent to the delivery of medical or surgical care to that child. This requirement reflects the application to minors of the tort law doctrine of informed consent, as well as principles under contract law. Traditionally, minors have been deemed incompetent as a matter of law to give informed consent to medical and surgical care and incompetent to enter into binding contracts, including contracts with physicians and surgeons. The rationales for parental consent requirements in the area of health care include the need to protect minors from their own improvident decisionmaking (based on the assumption that minors as a class lack the requisite capacity to make health care decisions), to promote family autonomy and privacy, to promote parental authority and control of minor children. Over the years, the number of exceptions to the parental consent requirement applicable to the health care of minors has grown significantly.

Parental notification requirement (applicable to health care of minors): A requirement that the parents of minors be notified of the decisions of their minor children to obtain health services. In carving out exceptions to the common law requirement for parental consent to the provision of health services to minors (see above), courts and legislatures have sometimes—though not always—replaced the parental consent requirement with a parental notification requirement. Thus, many parental notification requirements appear in laws that create exceptions to parental consent requirements by allowing minors to consent to health services related to sexual activities, health services for drug and alcohol abuse, or mental health services.

Pediatrician: A physician who specializes in the branch of medical science concerned with the hygienic, physiologic, and pathologic conditions of children.

Physician contact: As defined by the DHHS' National Center for Health Statistics for the *National Health Interview Survey*, any contact with a physician directly or with a nurse or other person acting under the physician's supervision, whether in person or by telephone, for the purpose of examination, diagnosis, treatment, or advice, excluding physician contacts with hospital *inpatients* or for the purpose of mass screenings (e.g., in a trailer). Compare *office visit*.

Poor: A term defined in relation to the *Federal poverty level*, a cash income level which varies with family size and the age of family members. Poor families are families with incomes below 100 percent of the Federal poverty level. The Federal poverty level for a family of three was $10,560 in January 1990. Compare *near-poor*.

Preferred provider organization (PPO): A group of health providers that contracts with employers, insurers, third party administrators, or other sponsoring groups to provide services on a discounted fee-for-service basis; health plan participants who use these providers pay lower deductible and coinsurance payments.

Pregnancy Discrimination Act of 1978 (Public Law 95-555): An act that amended the Civil Rights Act of 1964 and requires that employment-based health plans cover pregnancy, childbirth, or related medical conditions as they cover other medical care.

Prenatal care: Medical services related to fetal, infant and maternal health, delivered from time of conception to labor.

Preventive health services: Services intended to prevent the occurrence of a problem (e.g., disease or condition). **Primary prevention** is aimed at reducing the incidence of a disease or health problem; **secondary prevention** is aimed at reducing the prevalence of a problem by shortening duration among those who have the problem; and **tertiary prevention** is aimed at reducing complications. Preventive services typically recommended for adolescents include routine physical examinations, immunizations, and certain diagnostic tests (e.g., hematocrit, urinalysis), and preventive procedures including pap smears and screening for sexually transmitted diseases among the sexually active. Compare *treatment services*.

Primary care: Optimally, primary care includes the following elements: first contact care, comprehensive care, coordinated or integrated care, and care that is longitudinal over time rather than episodic. First contact care is the extent to which a patient contacts the source of care whenever he or she perceived a new need for care. Coordination of care entails a health care provider's ability to provide for continuity of information from visits to other providers (e.g., specialists and emergency facilities) as well as from earlier visits to him or herself. Longitudinality of care is the extent to which a provider serves as a source of care over time regardless of the presence or absence of a particular type of problem.

Primary prevention: See *preventive health services*.

Private health plan: See *employment-based group health plan*.

Problem behavior theory: The thesis that a variety of deviant or *problem behaviors* are all manifestations of a general dimension of conventionality versus unconventionality. In turn, the tendency toward conventionality or unconventionality is seen as arising out of three interacting systems of psychosocial influence: the personality system, the perceived environment, and the behavior system.

Problem behaviors (in adolescence): Those behaviors that have been deemed socially unacceptable or that lead to poor health outcomes (e.g., *unprotected sexual intercourse*, delinquent behavior, *substance abuse*).

Protective services: An aspect of *social services* designed to prevent neglect, abuse, and exploitation of children by reaching out with social services to stabilize family life (e.g., by strengthening parental capacity and ability to provide good child care). The provision of protective services follows a complaint or referral, frequently from a source outside the family, although it may be initiated by an adolescent him or herself.

Puberty: The period of becoming first capable of reproducing sexually, marked by maturing of the genital organs, development of secondary sex characteristics (e.g., breasts, pubic hair), and in humans and higher primates, the first occurrence of menstruation in the female.

Race: Races can be distinguished by usually inherited physical and physiological characteristics without regard to language or culture (caucasoids, negroid, mongoloid). By Census Bureau definition, the term race is used to distinguish among peoples who are white (caucasoid), black (negroid), or Asians or Pacific Islanders or American Indians (mongoloid). See *ethnicity, Hispanic, Indian.*

Racial and ethnic minorities: In this Report, anyone is who *not* "white, non-Hispanic." Includes black, Asian American, *Hispanic* and other adolescents.

Reproductive health care: Can include a wide range of services related to the male or female reproductive systems, including gynecological treatment services (i.e., examination and treatment of the female reproductive organs), and preventive services related to the use of contraception (e.g., counseling, prescribing contraceptive methods, dispensing contraceptives). See also *prenatal care.*

Restricted-activity day: As defined by the DHHS National Center for Health Statistics' *National Health Interview Survey*, any day on which a person cuts down on his or her usual activities for more than one-half day because of an illness or an injury. Restricted-activity days are unduplicated counts of: 1) **bed-disability days** (days on which a person stayed in bed more than half a day because of illness or injury or was in a hospital as an inpatient); 2) **work-loss days** (days on which a currently employed person 18 years of age and over missed more than half a day from a job or business); 3) **school-loss days** (days on which a student 5- to 17-years-old missed more than half a day from the school); and 4) **cut-down days** (days on which a person cuts down for more than half a day on the things he or she usually does). Work-loss, school-loss, and cut-down days refer to the short-term effects of illness or injury. Bed days are a measure of both long- and short-term disability, however, because a chronically ill bedridden person and a person with a cold could both report having spent more than half a day in bed due to an illness. See *restriction of activity.*

Restriction of activity: As used in the DHHS National Center for Health Statistics' *National Health Interview Survey*, ordinarily refers to a relatively short-term reduction in a person's activities below his or her normal capacity. See *restricted-activity day.*

Rural: As strictly defined by the U.S. Department of Commerce, Bureau of the Census, rural refers to places of 2,500 or fewer residents. (Census-recognized "places" are either: 1) incorporated places such as cities, boroughs, towns, and villages; or 2) closely settled population centers that are outside of urbanized areas, do not have corporate limits, and (unless they are in Alaska and Hawaii) have a population of at least 1,000.) The term "rural" is often used to refer to nonmetropolitan statistical areas (i.e., any area not in a metropolitan statistical area, which, as defined by the U.S. Office of Management and Budget, a county or group of counties that includes either a city of at least 50,000 residents, or an urbanized area with at least 50,000 people that is itself part of a county/counties with at least 100,000 total residents).

School-linked health center (SLHC): Refers to any school health center that provides a wide range of medical and counseling services for students (and sometimes for the family members of students and/or school dropouts) and is located either on or near school grounds and is associated with the school. May also include a wider range of services (e.g., child care, employment training, tutoring, social services, recreational opportunities). Compare *comprehensive services for adolescents.*

School-loss day: A day in which a student missed more than half a day from the school in which he or she was currently enrolled.

Secondary prevention: See *preventive health services.*

Self-insured (health insurance) plan: A health benefit plan in which the financial risk for providing medical services is assumed by the employer or sponsor instead of purchasing health insurance from an insurance company. The employer or sponsor may continue to contract with an insurance company or other organization for claims processing and administrative services, as well as stop-loss insurance to limit the amount of their liability for medical claims.

Sensitivity: One measure of the validity (or accuracy) of a diagnostic or screening test: the percentage of all those who actually have the condition being tested for who are correctly identified as positive by the test. Operationally, it is the number of true positive test results divided by the number of patients that actually have the disease or condition (true positives divided by the sum of true positives plus false negatives). Compare *specificity*.

Sexually transmitted disease (STD): Any infectious disease transmitted through sexual intercourse or genital contact. Examples are gonorrhea, chlamydia, herpes, and AIDS. Formerly (and sometimes, in law) called venereal disease.

Social environment: The aggregate of social and cultural conditions that influence the life of an individual or community. Aspects of the social environment particularly important to adolescents include the adolescents' families, other adults with whom adolescents come in contact, schools, workplaces, recreational facilities, and the media.

Social services: Service provided in order to support the functioning of individuals or family units, including those services termed: 1) "supportive" or "*protective services*"; 2) supplementary (i.e., financial assistance, home aid services (e.g., homemaker, caretaker, and parent aide services), respite care); and 3) "substitute" services (e.g., shelter services, foster care, adoption).

Socioeconomic status: Used in this Report as a synonym for income levels, typically those of an adolescent's family of origin, because adolescents are unlikely to have their own independent sources of income. See *poor, near-poor*.

Specificity: One measure of the validity (or accuracy) of a diagnostic or screening test: the percentage of all patients that do not have the condition being tested for that are correctly identified as negative by the test. Operationally, it is the number of negative test results divided by the number of patients that actually do not have the condition (true negatives divided by the sum of true negatives plus false positives). Compare *sensitivity*.

State: In this Report, the capitalized term State (whether used as an adjective or a noun) refers to 1 or more of the 50 United States. The term state (not capitalized) refers more generally to the body politic.

Statutory law: The body of law created by acts of the legislature in contrast to law generated by judicial opinions and administrative bodies.

Subjective distress: Feelings of sadness, hopelessness, discouragement, boredom, stress, dissatisfaction, or being worn out or exhausted, that are *self-reported* by individuals but are not necessarily symptoms of *diagnosable mental disorders*.

Substance abuse: What constitutes adolescent substance abuse (any use at all or "problem" use) is a matter of controversy. The DHHS Office of Substance Abuse Prevention is of the view that any use by adolescents of psychoactive substances by adolescents should be considered abuse; the American Psychiatric Association distinguishes between substance use, substance abuse, and *substance dependence*, although does not make distinctions by age. According to the American Psychiatric Association's diagnostic manual (DSM-III-R), substance abuse is characterized by maladaptive patterns of substance use that have never met the criteria for dependence for that particular class of substance, that results in harm to the user, and that the user continues despite persistent or recurrent adverse consequences.

Substance dependence: A mental disorder in which a person has impaired control of psychoactive substance use and continues use despite adverse consequences. It is characterized by compulsive behavior and the active pursuit of a lifestyle that centers around searching for, obtaining, and using the drug.

Supplemental Security Income (SSI) program: A Federal income support program for low-income disabled, aged, and blind persons, which was established by Title XVI of the Social Security Act. Eligibility for the program is based on income and resources.

Third-party payment: Payment by a private insurer or government program to a medical provider for care given to a patient.

Title V of the Social Security Act: See *maternal and child health block grants*.

Title X of the Public Health Service Act: Established by the Family Planning Services and Population Research Act of 1970, funds public or private nonprofit entities that operate voluntary family planning projects; funds training for personnel to improve the delivery of family planning services; promotes service delivery improvement through research; and develops and disseminates information on family planning. Contraceptives may be distributed without parental consent or notification, but the use of Title X funds for abortion as a method of family planning has been prohibited by statute and regulations. Low-income individuals are targeted as a priority group for receiving services. Although projects funded by Title X do not focus exclusively on adolescents, they are required to offer a broad range of family planning services to all who want them, including adolescents.

Title XX of the Public Health Service Act: Established by the Adolescent Family Life Act of 1981, provides Federal funds for demonstration projects to encourage adolescents to postpone sexual activity and demonstration projects to provide comprehensive services for pregnant and parenting adolescents.

Title XX of the Social Security Act: Established by the Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35), a program of *block grants* to States for the provision of social services, for the purpose of assisting individuals to: 1) achieve or maintain economic self-support; 2) achieve or self-sufficiency; prevent or remedy neglect, abuse, or exploitation of children and adults unable to protect their own interests; 4) prevent or reduce inappropriate institutional care; 5) secure referral or admission for institutional care when other forms of care are not appropriate, or provide services to individuals in institutions. Administered by the Office of Human Development Services in DHHS.

Tort: A private or civil wrong or injury, other than breach of contract, for which the court will provide a remedy in the form of an action for damages. A tort may be either: 1) a direct invasion of some legal right of the individual; 2) the infraction of some public duty by which special damage accrues to the individual; or 3) the violation of some private obligation by which special damage accrues to the individual. Three elements of every tort action are existence of legal duty from defendant to plaintiff, breach of duty, and damage as a proximate result.

Tort law: The branch of law pertaining to torts (see above).

Treatment services: Services intended to cure or ameliorate the effects of a disease of other health problem once the problem has occurred. Compare *preventive health services.*

Underclass: Definitions of ''underclass'' vary. There is considerable controversy concerning whether the definition should be restricted to residence in an area characterized by a specific level of demographic characteristics (e.g., low earned income, low educational attainment, and low labor market participation) or be expanded to include attitudinal/behavioral dimensions (e.g., alienated, unmotivated).

Unprotected sexual intercourse: Sexual intercourse without precautions taken to prevent pregnancy or the transmission of *AIDS* or *sexually transmitted diseases.*

Venereal disease: See *sexually transmitted disease.*

Well-child care: Preventive health care for children, including immunizations, health education, parental guidance, physical examinations and other tests that screen for illness or developmental problems.

Younger adolescents: As defined in most studies and data analyses, adolescents ages 10 to 14.

Appendix B
BURDEN OF HEALTH PROBLEMS AMONG U.S. ADOLESCENTS

OTA's analysis in Volume II, based on a broad range of measures of adolescent health and a wide variety of sources of data, suggests that the conventional wisdom that American adolescents as a group are so healthy that they do not require health and related services is not justified. OTA's findings regarding the burden of health problems among U.S. adolescents are summarized in the table below.

In considering the estimates in this appendix, it is important to note several limitations of the available data, in particular:

- The data here on prevalence and incidence come from widely varying sources. When national data were not available, more limited sources are used and such sources are noted. However, even national data have their limitations.
- A particular shortcoming of available data on adolescents apparently "most at risk" of specific problems (see last column) is that, although disaggregations of health status information by gender, race, ethnicity, and age are often difficult to obtain, such data are more likely to be available than crosstabulations of data providing valid information about the *causes* of differences in health status. For example, meaningful data on socioeconomic status and health, and the interactions of socioeconomic status with other factors, are particularly lacking in the United States. But information on the relationships among a wide range of biological (e.g., genetic), psychological (e.g., perceptual), behavioral (e.g., engagement in risk-taking behaviors such as sports), and social (e.g., family income, community) factors and particular health problems, and the relationships of health problems with each other, is scarce. Typically, special research studies are required (and have sometimes been conducted) to determine the relationships of the broad range of possibly explanatory factors to adolescent health problems. The availability of such studies is discussed in specific chapters in Volume II of this Report (also see ch. 18, "Issues in the Delivery of Services to Selected Groups of Adolescents," in this volume). Some of the information from special research studies is reflected in the table below, but, often, the only information available is by gender and/or racial and ethnic background. In considering the information shown below, it is important not to confuse mere correlations of racial, ethnic, gender, and other (e.g., income) factors with causality.

For a complete understanding of the sources and limitations of each data point presented here, the interested reader is encouraged to consult the specified chapters in Volume II of this Report, *Background and the Effectiveness of Selected Prevention and Treatment Services*. A synthesis of the crosscutting issues in data collection and dissemination with respect to adolescent health can be found in Appendix C, "Issues Related to the Lack of Information about Adolescent Health and Health and Related Services," in Volume I of this Report, *Summary and Policy Options*.

Problem	Prevalence, incidence, or other measure of burden	Adolescents most at risk according to available data[1]
Family problems[2]	Full scope unknown. In 1985, between 620,000 to 720,000 adolescents ages 10 to 17 were maltreated.[3] An estimated 120,000 adolescents between ages 13 and 18 were in foster care in 1985. In 1984, about one-third of females and one-fifth of males using runaway and homeless youth centers reported that physical or sexual abuse was a problem that led to their running away.[4]	Many homeless adolescents report having been abused (physically and sexually) prior to becoming homeless. Females seem to be at greater risk than males (especially for sexual abuse). Adolescents in "authoritarian" or "overindulgent" families and adolescents in families with a stepparent are at increased risk.

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[1] See caveats above regarding available data, particularly on gender and racial factors.

[2] See ch. 3, "Parents' and Families' Influence on Adolescent Health," in Vol. II.

[3] These data are based on data from the U.S. Department of Health and Human Services' (DHHS) National Center on Child Abuse and Neglect. Maltreatment was defined by DHHS as instances where "a child's health or safety is seriously endangered."

[4] These data are from the fiscal year 1984 annual report for runaway youth centers prepared by the Administration for Children, Youth, and Families in DHHS. See ch. 14, "Homelessness: Prevention and Services," in Vol. II.

Problem	Prevalence, incidence, or other measure of burden	Adolescents most at risk according to available data[1]
School problems[5]	In October 1988, the status dropout rate[6] for individuals ages 16 to 24 was 12.6 percent (4 million individuals).	Hispanic adolescents (status dropout rate of 33.0 percent); adolescents in central cities (status dropout rate of 15.4 percent); black adolescents (status dropout rate of 13.8 percent).
Injuries:		
• Nonfatal injuries[7]	National survey data indicate about one-third of children (ages 5 to 17) experienced an accidental or intentional injury in 1988.[8] In 1985, accidental and intentional injuries (and poisonings) accounted for 8,177,000 visits to physician offices among adolescents ages 10 to 18. In 1987, accidental and other injuries accounted for 25 percent of hospitalizations for males ages 10 to 14 and 33 percent of hospitalizations for males ages 15 to 18.[9] Playing basketball, football, or baseball and riding a bicycle accounted for 772,000 emergency room visits by adolescents in 1988.[10]	Adolescents who engage in risk-taking behavior (e.g., participation in contact sports). Adolescents who are physically abused.
• Accidental injury deaths	Accidental injuries are the leading cause of death among adolescents. In 1987, 12.9 percent of all deaths to adolescents ages 10 to 14 and 46.2 percent of all deaths to adolescents ages 15 to 19 were due to accidental injuries. In 1987, there were 10,658 accidental injury deaths among 10- to 19-year-olds.[11] The vast majority (74 percent) of those accidental injury deaths are due to vehicle-related injuries; others are due to drowning (8 percent), accidental firearms injuries (4 percent), and other causes (15 percent).	Adolescents who engage in risk-taking behavior (e.g., consumption of alcohol, unsafe driving; failure to use automobile safety belts). Adolescents ages 15 to 19 are at greater risk than adolescents ages 10 to 14. Males, especially ages 15 to 19, are at considerably greater risk than females.[12] American Indian and Alaska Native adolescents experience death from accidental injury at twice the rate of blacks or whites. White male adolescents and American Indian and Alaska Native adolescents (both sexes combined) have the highest rates of motor-vehicle-related accidental deaths. Black male adolescents have higher rates of drowning deaths than white adolescents of either sex and black female adolescents.
• Suicide deaths[13]	In recent years, adolescent suicide rates have apparently increased. There were a total of 2,152 officially reported suicides among 10- to 19-year-olds in 1987. In 1987, 1.5 percent of all deaths to adolescents ages 10 to 14 and 10.3 percent of all deaths to adolescents ages 15 to 19 were due to suicide.	Adolescents who have made a previous suicide attempt. White males ages 15 to 19 have higher suicide rates than either white females or blacks. American Indian adolescents have much higher suicide rates than white adolescents.

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[5] See ch. 4, "Schools and Discretionary Time," in Vol. II.

[6] The *status dropout rate* is the proportion of individuals who are not enrolled in school and have not finished high school at any given point in time. These calculations are based on Current Population Survey (a household-based survey) data from the U.S. Department of Commerce, Bureau of the Census.

[7] See ch. 5, "Accidental Injuries: Prevention and Services," in Vol. II.

[8] From DHHS' National Health Interview Survey. For adolescents under age 17, the data are reported by a proxy respondent, usually the mother.

[9] Utilization data on physician visits from DHHS' National Ambulatory Medical Care Survey, and utilization data on hospitalizations from DHHS' National Hospital Discharge Survey.

[10] From the U.S. Consumer Product Safety Commission.

[11] In 1987, there were 2,130 accidental injury deaths among 10- to 14-year-olds (12.9 deaths per 100,000) and 8,528 accidental injury deaths among 15- to 19-year-olds (46.2 deaths per 100,000). Mortality statistics are gathered by DHHS' National Center for Health Statistics.

[12] The male-to-female ratio differs by cause of death. For example, from 1984-86 the differences in the male-to-female ratio ranged from 9.9:1 for deaths due to drowning to 1.5:1 for homicide.

[13] See ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II. Mortality statistics are gathered by DHHS' National Center for Health Statistics.

Problem	Prevalence, incidence, or other measure of burden	Adolescents most at risk according to available data[1]
• Homicide deaths[14]	There were approximately 2,100 adolescent homicide victims in 1987. In 1987, 1.6 percent of all deaths to adolescents ages 10 to 14 and 10.0 percent of all deaths to adolescents ages 15 to 19 were due to homicide.	In 1985, 689 black males ages 10 to 19 died as compared with 657 white males, but there were almost 5.5 times as many white males as blacks in the population. The races and ages of those committing adolescent homicides are unknown.
Chronic Physical Illnesses[15]:		
• Serious chronic physical illness	An estimated 5 to 10 percent of adolescents have a chronic condition (e.g., leukemia, cerebral palsy, hearing or visual impairment) that limits their activities.[16]	Adolescents of low socioeconomic status (e.g., family incomes of less than $10,000) are more likely to have a limitation in a major activity as a result of a chronic condition (9.8 percent have limitations) than adolescents of higher socieconomic status (e.g., family income of more than $35,000) (5.1 percent have limitations).
• Significant physical problem that could interfere with development	Unknown. Latest available data (from 1970) indicate 22 percent of adolescents have such a problem.[17]	
• Acne[18]	80 to 90 percent of adolescents experience some degree of acne at some time.	Males, white adolescents tend to have more serious problems.
• Dysmenorrhea (difficult and painful menstruation)[18]	National data not available, but local surveys suggest that 25 to 45 percent of female adolescents have missed some school or work because of dysmenorrhea.[19]	Females only.
Nutrition and Fitness Problems[20]	Many adolescents suffer from some nutritional or fitness problem.[21]	*Nutritional deficiencies*: Female adolescents, adolescent athletes of both sexes, adolescents with chronic physical or mental illness or disabilities, and homeless and runaway adolescents. *Obesity*: Available information suggests problems with obesity for black female adolescents, Mexican Americans, Native Hawaiians, American Indians and Alaska Natives, Samoans, and Tongans of both sexes.
Dental and Oral Health Problems[22]:		
• Dental caries (cavities)	Full extent unknown, but declining. From 1980 to 1987, caries prevalence among adolescents in school declined 20 to 40 percent.[23] According to a national school-based survey in 1987, 44 percent of 10-year-olds had experienced caries, while 84 percent of 17-year-olds had experienced caries. However, 22 percent of 10-year-olds and 12 percent of 17-year-olds needed fillings (restorations) for their decayed teeth in 1987.	Adolescents without access to fluoridated water or fluoride treatments are at increased risk for dental caries. Nonwhite (especially American Indian) adolescents have a higher percentage of untreated caries than white adolescents.[24] Juveniles in juvenile justice facilities have more decay, too. Small group of adolescents with rampant caries.[25]
• Severe malocclusion	Unknown. Latest available data (from 1970) indicate 13 to 16 percent of 12- to 17-year-olds have severe to very severe malocclusion.	

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[14] See also, ch. 13, "Delinquency: Prevention and Services, in Vol. II, and ch. 18, "Issues in the Delivery of Services to Selected Groups of Adolescents," in this volume. Mortality statistics are gathered by DHHS' National Center for Health Statistics.

[15] See ch. 6, "Chronic Physical Illnesses: Prevention and Services," in Vol. II.

[16] This estimate is based on information from DHHS' National Health Interview Survey. See ch. 6, "Chronic Physical Illnesses: Prevention and Services," in Vol. II, for information on how the estimate was derived.

[17] Based on data from DHHS' National Health Examination Survey (conducted in 1967-70), which included an examination by a physician.

[18] Acne and dysmenhorrea were selected as representative of health problems of special concern to adolescents.

[19] Based on data from local surveys. In the most recent national survey (the National Health Examination Survey conducted in 1967-70), 60 percent of adolescents who had begun to menstruate experienced menstrual pain, and 14 percent reported frequent school absenteeism due to dysmenorrhea.

[20] See ch. 7, "Nutrition and Fitness Problems: Prevention and Services," in Vol. II.

[21] Data on adolescents' nutrition and fitness problems come from a number of sources, among them the U.S. Department of Agriculture's Nationwide Food Consumption Surveys and DHHS' National Health and Nutrition Examination Surveys.

[22] See ch. 8, "Dental and Oral Health Problems: Prevention and Services," in Vol. II.

[23] From surveys of school-based children conducted by DHHS' National Institute of Dental Research.

[24] Available data do not separate the effects of race from income level or other relevant factors.

[25] Rampant caries is a rapidly progressing form of dental caries which involves extensive breakdown of enamel and dentin, and pulpal pathosis.

Problem	Prevalence, incidence, or other measure of burden	Adolescents most at risk according to available data[1]
• Periodontal disease	In 1987, many adolescents in school ages 14 to 17 experienced some gingival inflammation, but few have more serious gingival problems (e.g., 22 percent experienced periodontal attachment loss of more than 2 mm); 0.1 percent to 2.3 percent of U.S. adolescents have localized juvenile periodontitis.	Adolescents who do not have good oral hygiene; adolescents who use smokeless tobacco. Nonwhite adolescents (especially American Indians) have worse periodontal health than white. Disabled adolescents. Periodontal problems increase by age throughout adolescence and into adulthood.
AIDS and Other Sexually Transmitted Diseases (STDs)[26]:		
• STDs	The national prevalence and incidence of STDs other than gonorrhea and syphilis are unknown.[27] In 1989, 30 percent of newly reported gonorrhea cases and 10 percent of newly reported syphilis cases in the U.S. occurred among 10- to 19-year-olds.	Sexually active adolescents only, especially those who do not use condoms or who have multiple sexual partners. In 1988, about 64 percent of adolescent males ages 15 to 18 had ever had sexual intercourse and about 53 percent of adolescent females ages 15 to 19 had ever had sexual intercourse. Only 20 percent of sexually active female adolescents ages 15 to 19 reported current condom use.
• AIDS/HIV infection	AIDS: 568 cases among 13- to 19-year-olds as of September 1990.[28] HIV infection: prevalence unknown, but estimates run as high as 3.7 percent in a sample of runaway and homeless adolescents in New York City age 18 and under.[29]	Black, non-Hispanic adolescents ages 13 to 19 accounted for 36 percent of all adolescent AIDS cases through August 1990; Hispanic adolescents ages 13 to 19 accounted for 18 percent. Sexually active adolescents, especially those who engage in unsafe sexual practices (e.g., no condoms, multiple sexual partners). Also intravenous drug users who share needles and their partners; adolescents with hemophilia. Homeless and runaway adolescents.
Pregnancy and Parenting[30]:		
• Sexual activity[31]	In 1988, 53 percent of adolescent females ages 15 to 19 had ever had sexual intercourse. In 1988, about 64 percent of adolescent males ages 15 to 18 had ever had sexual intercourse.	Higher rates of sexual activity among homeless and runaway adolescents, blacks, Hispanics, adolescents of lower socioeconomic status.
• Contraceptive use[31]	In 1988, 20 percent of sexually active female adolescents ages 15 to 19 reported current condom use.	Higher contraceptive use among non-Hispanic white adolescents, adolescents of higher socioeconomic status, older adolescents.
• Pregnancy[32]	About one million U.S. adolescents become pregnant each year. In 1988, there were 110 pregnancies per 1,000 females adolescents ages 15 to 19. Pregnancy rates for sexually active adolescents ages 15 to 19 declined between 1970 and 1985.	Sexually active females who do not use effective contraceptive methods. Higher pregnancy rates among black and Hispanic adolescents of lower socioeconomic status; American Indian, Native Hawaiian adolescents; homeless and runaway adolescents.
• Abortion[32]	In 1984, over 400,000 adolescents obtained abortions. In 1984, 41 percent of all pregnancies to females ages 15 to 19 (44 per 1,000 females ages 15 to 19) and 56 percent of pregnancies to adolescents under age 15 (8.3 per 1,000 females under age 15) ended in abortion.	Pregnant females who both want and are able to obtain an abortion. In 1983, abortion rates as a percentage of pregnancies were higher for white adolescents (40.5 percent of white adolescent pregnancies) than black adolescents (38.1 percent of black adolescent pregnancies).

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[26] See ch. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services," in Vol. II.

[27] DHHS' Centers for Disease Control only collects data on two sexually transmitted diseases other than AIDS/HIV—gonorrhea and syphilis.

[28] These are AIDS data from DHHS' Centers for Disease Control's monthly "HIV/AIDS Surveillance" report.

[29] Among homeless and runaway adolescents staying at Covenant House in New York, 3.7 percent tested positive for HIV; see ch. 14 "Homelessness: Prevention and Services," in Vol. II, for more information.

[30] See ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II.

[31] These data are from DHHS' National Survey of Family Growth conducted periodically by the National Center for Health Statistics.

[32] Based on information from the Alan Guttmacher Institute.

Problem	Prevalence, incidence, or other measure of burden	Adolescents most at risk according to available data[1]
• Childbearing[33]	In 1988, there were 488,941 births to females under age 20. In 1984, 45.6 percent of all pregnancies to 15- to 19-year-olds.	Pregnant females who do not want or cannot obtain an abortion. For adolescents ages 15 to 19 in 1984, birth rates were higher for black adolescents (96 births per 1,000 black adolescent pregnancies) than for white adolescents (44 per 1,000 white adolescent pregnancies).
• Out-of-wedlock childbearing[33]	In 1988, about 65 percent of the 488,941 babies born to adolescents under age 20 were born out of wedlock (322,406 births, including 312,499 to females ages 15 to 19 and 9,907 to females under age 15 (92 percent of births to adolescent females under 15)).	Adolescents of lower socioeconomic status are more likely to have children out of wedlock than adolescents of higher socioeconomic status. Black females are more likely to bear children out of wedlock than white females.
• Adoption[34]	Less than 10 percent of all adolescents who become pregnant choose adoption.	Adolescents of higher socioeconomic status are more likely to choose adoption than adolescents of lower socioeconomic status. In 1982, 7.4 percent of white adolescents and 1 percent of black adolescents put their babies up for adoption.
Mental Health Problems[35]:		
• Diagnosable mental disorders[36]	National data are not available. A series of local studies show that an estimated 18 to 22 percent of adolescents have one or more diagnosable mental disorders.[37] The most common disorders are attention deficit disorder, oppositional disorder, conduct disorder, and separation anxiety disorder. Prevalence varies by disorder.	Homeless and runaway adolescents. Males; middle and older adolescents; low socioeconomic status adolescents.
• Subjective distress[38]	Varies by measure: The National Adolescent Student Health Survey of 8th and 10th graders[39] found in 1987 that, on average, 45 percent of respondents found coping with stressful situations at home and school "hard" (29.8 percent) or "very hard" (15.6 percent), 61 percent felt sad and hopeless in the past month either "sometimes" (36.9 percent) or "often" (13.2 percent). The University of Minnesota Adolescent Health Survey[40] found that, on average across grade levels, up to 28 percent of 7th through 12th graders reported experiencing "extreme stresses and strains"; up to 25 percent reported that they were dissatisfied with their personal lives; up to 23 percent reported that life was uninteresting; up to 26 percent reported that they were tired or worn out; and 19 percent reported that they were not feeling emotionally secure—all in one month before the survey.	Females, American Indians and Alaska Native adolescents; on one measure, rural males.[41]

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[33] Based on data gathered by DHHS' National Center for Health Statistics.

[34] From S.L. Hofferth, "Teenage Pregnancy and Its Resolution," *Risking the Future: Adolescent Sexuality, Pregnancy, and Childbearing. Volume II: Working Papers and Statistical Appendixes*, S.L. Hofferth and C.D. Hayes (eds.) (Washington, DC: National Academy Press, 1987).

[35] See ch. 11, Mental Health Problems: Prevention and Services," in Vol. II.

[36] Diagnosable mental disorders (e.g.. conduct disorder, separation anxiety disorder, depression) are included in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, 3rd ed., revised (DSM-R-III).

[37] See table 11-1 in ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II, for a sample of studies on the prevalence of DSM-III diagnoses among adolescents.

[38] Subjective distress is not necessarily, but is possibly, related to a mental health problem.

[39] The National Adolescent Health Survey, conducted in 1987, sampled 8th and 10th graders and relies on self-reported information.

[40] The Adolescent Health Survey, conducted by the University of Minnesota, sampled 7th through 12th graders in the State of Minnesota and relies on self-reported information.

[41] Of Minnesota adolescents (mostly white, non-Hispanic) surveyed, rural males were most likely to report that "life is uninteresting."

Problem	Prevalence, incidence, or other measure of burden	Adolescents most at risk according to available data[1]
• Suicide attempts	Full extent unknown. In 1987, however, 13 percent of 8th and 15 percent of 10th graders surveyed reported having made a suicide attempt.[42]	Adolescents who have experienced family disruption (divorce, death, abandonment); abused adolescents; homeless and runaway adolescents; gay and lesbian adolescents; adolescents with substance abuse problems. White females; American Indians and Alaska Natives.
Alcohol, Tobacco, and Drug Abuse[43]:		
• Alcohol use	Extent of abuse unknown. In 1989, 4.2 percent of high school seniors reported daily use of alcohol. In 1987-89, 15.8 percent of 10th graders and 11.1 percent of high school seniors reported recent heavy drinking.[44]	Adolescents whose parents, siblings, or peers use alcohol; homeless and runaway adolescents; American Indian adolescents.
• Tobacco use	In 1989, 18.9 percent of high school seniors reported daily cigarette smoking.[45] In 1987, 4.4 percent of 10th grade males used smokeless tobacco.[46]	Adolescents whose parents, siblings, or peers smoke. Adolescents in families of lower socioeconomic status.
• Illicit drug use:	Full extent of abuse unknown. In 1989, 2.9 percent of high school seniors reported daily use of marijuana or hashish; 0.3 percent reported daily use of cocaine; 0.3 percent reported daily use of hallucinogens; 0.3 percent reported daily use of inhalants.	White, non-Hispanic adolescents, then Hispanic adolescents, then black adolescents.[47] Availability of income positively related to use of illicit drugs among students. Some evidence that adolescents with mental health problems more likely to be problem users of drugs. American Indian adolescents. Homeless and runaway adolescents.
Delinquent behavior[48]:	Estimates vary, depending in part on whether they are based on official arrest records or on data from self-reports or reports of victims.[49] In 1988, there were 1.6 million arrests of adolescents. In 1987, about 700,000 adolescents were confined to public or private juvenile justice facilities.[50] [51]	In comprehensive self-report surveys, almost all adolescents report having committed some delinquent act (typically not a serious delinquent act). Homeless and runaway adolescents (prostitution, panhandling, drug dealing).
• Serious violent offenses	Arrest data and victims' reports show an overall decline since the mid-1970s. However, in 1987, the number of adolescents held in public facilities for serious violent offenses increased for the first time since 1983. For aggravated assault, murder, and nonnegligent manslaughter, arrest data show an increase in recent years; for robbery and forcible rape, they show a decrease.	15- to 17-year-old males, black males, males living in urban areas. The gender gap for arrest rates is narrowing—from 11.4 (males):1 (females) in 1965 to 7.5:1 in 1987 for serious violent offenses.
• Serious property offenses	Arrest data show a major overall decline since the mid-1970s.	15- to 17-year-old males, black males, males living in urban areas, though the gender gap in arrest rates is narrowing—from 6.7 (males):1 (females) in 1965 to 3.6:1 in 1987 for serious property offenses.

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[42] From the National Adolescent Student Health Survey, a one-time self-report survey of 8th and 10th graders in 1987.

[43] See ch. 12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II.

[44] Heavy drinking is defined as having had 5 or more drinks "on one occasion" (National Adolescent Student Health Survey wording) or "in a row" (Monitoring the Future/High School Seniors Survey wording) in the 2-week period prior to the survey.

[45] Among high school seniors, 7.7 percent smoked 1 to 5 cigarettes daily; 4.4 percent smoked one pack of cigarettes daily, and 11.2 percent reported smoking half a pack of cigarettes or more per day (Monitoring the Future/High School Seniors Survey).

[46] From the National Adolescent Student Health Survey, a one-time self-report survey of 8th and 10th graders in 1987.

[47] From DHHS' National Institute on Drug Abuse national household survey data.

[48] See ch. 13, "Delinquency: Prevention and Services," in Vol. II.

[49] See table 13-1 in ch. 13, "Delinquency: Prevention and Services," in Vol. II, for information about the four principal sources of national data on the prevalence, incidence, and demographic correlates of adolescent delinquency: 1) the Uniform Crime Reports, 2) the National Crime Survey, 3) the National Youth Survey, 4) the Monitoring the Future/High School Seniors Survey.

[50] From the U.S. Department of Justice's Office of Juvenile Justice and Delinquency Prevention statistics.

[51] For purposes of counting arrests and detentions, "juvenile" is a legal term. A *juvenile* is a person subject to juvenile court jurisdiction for purposes of adjudication and treatment based on age and offense limitations defined by State law. The upper age of original juvenile court jurisdiction ranges from 16 to 19, but for most States is 17 or 18.

Problem	Prevalence, incidence, or other measure of burden	Adolescents most at risk according to available data[1]
Homelessness[52]	Unknown, although DHHS estimated in 1984 (on the basis of 1976 data) that there are as many as 1 million homeless and runaway adolescents each year.[53]	Adolescents who leave home because of physical, sexual or emotional abuse; adolescents with substance-abusing parents; adolescents in foster care; formerly institutionalized (e.g., juvenile justice, mental health system) adolescents; adolescents in homeless families; gay adolescents.
Poverty	17 percent (5.3 million) of adolescents live below the Federal poverty level; another 10 percent (3.0 million) are "near poor" (family incomes between 100 and 149 percent of the Federal poverty level).	Adolescent mothers; adolescents living in single parent female-headed households; black, Hispanic, Asian, American Indian and Alaska Native adolescents; Native Hawaiian adolescents; rural adolescents.
Multiple problems	Full extent unknown. In 1987, using problem behavior theory as a guide, Dryfoos estimated that 10 percent of adolescents ages 11 to 17 are at very high risk of multiple *behaviorally* based problems; another 40 percent are at medium risk.[54] Research on covariation is limited.[55]	Homeless and runaway adolescents.

[52] See ch. 14, "Homelessness: Prevention and Services," in Vol. II.

[53] The 1990 census made efforts to count homeless persons, but it is unlikely that it will produce an accurate count.

[54] Based on data from J. Dryfoos, *Adolescents at Risk* (New York, NY: Oxford University Press, 1990).

[55] *Covariation* is the tendency of health problems to occur in the same individual at about the same time. Most of the evidence on covariation of adolescent problems is based on cross-sectional studies, so it is still unclear for many problems whether one problem leads to another or the problems occur together, due to a single cause of set of causes (see D.W. Osgood and J.K. Wilson, "Covariation of Adolescent Health Problems," paper prepared under contract to Carnegie Council on Adolescent Development and Carnegie Corporation of New York, for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1990 (Springfield, VA: National Technical Information Service, NTIS No. PB 91-154 377/AS)). Another limitation of the evidence on covariation is that most of the evidence is limited to covariation in adolescent behaviors and does not consider emotional or physical problems.

SOURCE: Office of Technology Assessment, 1991, based on data presented in various chapters in Vol. II of this Report, and in ch. 18, "Issues in the Delivery of Health and Related Services," in this volume.

Appendix C

HCFA'S METHOD FOR ESTIMATING NATIONAL MEDICAID ENROLLMENT AND EXPENDITURES FOR ADOLESCENTS AGES 10 THROUGH 18

To develop estimates of national Medicaid enrollment and expenditures for adolescents ages 10 through 18, the Health Care Financing Administration (HCFA) within the U.S. Department of Health and Human Services used the method outlined below.

To Develop National Estimates for Ages 6 to 14 and 15 to 20 Combined

1. Thirty-five States (Alabama, Arkansas, Arizona, Colorado, District of Columbia, Florida, Georgia, Idaho, Illinois, Iowa, Kansas, Louisiana, Maine, Maryland, Massachusetts, Mississippi, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia) reported data in fiscal year 1988 on Medicaid enrollees (ever-enrolled), Medicaid recipients (those who used at least one covered service during the year), and Medicaid expenditures for age groups 6 to 14 and 15 to 20 (new form HCFA-2082).
2. The remaining States, Puerto Rico, and the Virgin Islands reported Medicaid recipients and expenditures only (no enrollees) and only for the age group 6 to 20 (old form HCFA-2082).
3. The Medicaid enrollee and expenditures totals for age groups 6 to 14 and 15 to 20 for the 35 States listed in step 1 were blown up to national totals using ratios developed from the recipient and expenditure data for age group 6 to 20 (available in all States). The blowup factors for expenditures were calculated on a service-by-service basis. (On average, the 35 States in step 1 accounted for about 58 percent of Medicaid recipients and 63 percent of aggregate expenditures for the age group in question).

To Develop Separate Estimates for Ages 10 to 14 and 15 to 18

4. The number of Medicaid enrollees in the 10 to 14 and 15 to 18 age groups was derived from the above counts for ages 6 to 14 and 15 to 20, respectively, by applying ratios calculated from data on Medicaid-covered persons from the March 1989 Current Population Survey. The age distributions from the Current Population were first smoothed to eliminate some fluctuation in the counts from age to age (primarily in the teen years).
5. Average costs per enrollee by service category for age groups 6 to 14 and 15 to 20 were calculated using the results of steps 1 through 3. Averages for age groups 10 to 14 and 15 to 18 were estimated by interpolation using an exponential cost function whose parameters were calculated to reproduce average costs for the age group 6 to 14 and 15 to 20.

Limitations

- Medicaid expenditure data are on a date-of-vendor-payment basis rather than a date-of-service basis, as one would normally like to have. This means that, because of payment lags, the fiscal year 1988 expenditures in the numerators of the per-enrollee costs relate to a slightly different population from the enrollee counts in the denominators.
- Medicaid enrollee counts are of individuals ever-enrolled during the fiscal year rather than the more desirable person-year counts. Data from other sections of form HCFA-2082 can be used to develop person-year counts, but not by age group. The closest HCFA can come to the population of interest here is Aid to Families With Dependent Children, who show averages of about 9 months of enrollment during a fiscal year. Thus, for children, per capitas based on person-years would be about one-third higher (12/9) than those based on ever-enrollment counts.
- Age-unknown cells were ignored in the calculations. This fact plus internal inconsistencies within form HCFA-2082 mean that aggregate (all-age) expenditure totals derived from our tables will fall somewhat short (perhaps about 0.5 percent) of published totals.
- In general, the data HCFA used for these estimates come from infrequently used sections of form HCFA-2082 and have not, to HCFA's knowledge, been subject to a great deal of analysis. HCFA adjusted for some obvious reporting problems discovered, but other data problems may remain. Consequently, the estimates should be considered provisional.

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, Office of the Actuary, unpublished HCFA-2082 data on Medicaid expenditures and enrollment in fiscal year 1988, Baltimore, MD, June 1990.

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